‘Navigating their way’

How do women with hospitalised premature infants perceive their roles in regional special care nurseries?

Catherine Knox

R.N. R.M. IBCLC.

Grad. Dip. Midwifery (Aquinas, ACU)

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School of Nursing

University of Ballarat

PO Box 663

University Drive

Mount Helen, Ballarat

Victoria 3353

Australia

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You're neither here nor there… I was all over the place, I felt very fragmented. **[Participant]**

Abstract

Improved survival rates for premature infants have resulted in extended hospital stays in neonatal nurseries with consequent challenges for mothers assuming a parental role. Additionally, maternal medical complications associated with surgical birth, and a need to locate themselves in unfamiliar clinical environments, exacerbate women's experiences and transition to a maternal role competes with other roles at this time. For women living in rural and regional areas, who experience premature birth, there is additional hardship due to isolation, distance and limited support services. There has been little research on women's experiences with infants in special care nurseries (SCNs) in regional Australia.

The ways in which mothers 'navigate their way', physically and emotionally, in SCN environments was the focus of this study. Using a qualitative interpretive design, underpinned with a postmodern feminist perspective, data were collected through in-depth interviews with eight mothers and analysed thematically. Women related a dislocation in their lives as a result of their infant's hospitalisation. The women's accounts revealed the ways the nursery space impacted on them, and the conflicting roles they adopted throughout this time were perceived as difficult. These findings provide direction for developing more supportive environments for parents relying on SCNs for the care of their infant.

Through interpretations of women's stories, this study provides new understandings of the ways in which women view themselves and their environmental sensitivity within SCN settings. Findings will increase regional midwives' understanding of mothers' interpretations of the neonatal nursery environment. Insights into maternal perspectives will assist in the

provision of better family-centred care and improved outcomes for the vulnerable families of premature infants.

Statement of Authorship

Except where explicit reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis by which I have qualified for or been awarded another degree or diploma. No other person's work has been relied upon or used without due acknowledgement in the main text and bibliography of the thesis.

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Chapter 1: Introduction

> A new mother, with a premature baby in the nursery, is lost without a map. She is a mother with a baby she can only 'visit' - her pregnancy is being completed in an institution. Her baby rests in an artificial womb, gestating, cared for by others. Her working life, if she had one, has been prematurely terminated, her maternity leave has abruptly begun; society assumes mothers will always be the primary caregiver. She complies with the special care nursery rules and regulations, and seeks to navigate her way through the physical and cultural constraints of this environment. The metamorphic process of becoming a mother takes place in public, under the scrutiny of staff, who take over the care of her baby (Knox, Personal journal, 11/8/05).

> She comes in and says 'I love you' and cuddles her baby and I want her to say that to all the babies because no-one else does (Knox, Personal journal- staff member describing a mother's interaction in the nursery, 2/2/06).

The birth of a baby is generally a much anticipated and exciting event; however, when an infant is born prematurely, expectations are dramatically altered. Over the last two decades, advanced technology and improvements in care of extremely premature infants has resulted in the survival of increasingly tiny infants (Ward & Beachy, 2003). Premature birth results in infants needing special care, either in a neonatal intensive care unit (NICU) or special care nursery (SCN) depending on their condition.

This research study sought to gain an understanding of women's perceptions of their roles within regional SCN environments when their premature infant was an inpatient.
In Victoria, NICUs, which require specialist staff and equipment, are located in the major urban centre of Melbourne. Women in rural and regional centres, who give birth to an infant requiring high dependency care with resultant transfer to a tertiary centre, have to

contend with additional hardship. The bed occupancy in NICUs often exceeds their capacity resulting in early transfer back to SCNs in regional centres. Consequently, premature infants of women from rural and regional communities may be hospitalised in regional nurseries for an extended length of time.

Premature infants in SCNs are generally medically stable and maturing to a sufficient size before discharge. In this environment, mothers potentially have the capacity to become more involved with their infant's care and develop their parental role. There is an expectation by both staff and parents in SCNs for greater parental participation in infant care as the infant approaches discharge (Gracey, 2004; Scharer & Brooks, 1994). A preliminary literature search revealed a paucity of published research specific to mothers' experiences in SCNs, most related to NICUs, although some studies incorporated both NICU and SCN settings into their investigations. There was little attention in this literature regarding the impact of parental geographical setting. Recommendations for further research following development of Australian guidelines for premature birth included investigating the needs of mothers and families of premature infants (National Health and Medical Research Council [NHMRC], 2000). It was my intention to focus specifically on this SCN environment and identify any themes peculiar to SCNs in regional settings in the context of women's roles.

Motherhood continues to be examined from various perspectives, including feminist, sociological and psychological discourses. Richards (1997) claimed '...motherhood has all the characteristics of an ideology' (p. 176) and the importance and ideological load of

mothers is taken for granted in society. The recent ‘professionalisation’ of motherhood has to a certain extent, resulted in prescribed behaviour for mothers (Phoenix & Woollett, 1991; Summers, 2003); many women may find it difficult to ‘mother well’ within these constraints. The contradictions and difficulties associated with parenting are receiving an increasing interest in Australian media whether promoting or denouncing motherhood (Fedler, 2006; Legge, 2005) and publications as well as workshops for parenting skills are prolific. Consequently, expectations of motherhood have possibly never been higher. Importantly, it has been noted that neonatal nurses have specific expectations of mothers’ behaviour in order to be seen as a ‘good mother’ (Fenwick, Barclay & Schmied, 2001b) with parental caregiving skills needing to be ‘mastered’ prior to the infant going home (Bruns, McCollum, & Cohen-Addad, 1999, p. 281). Possible medical or obstetric complications of women following birth and ensuing separation from their premature infant result in these women being deprived of early, uninterrupted contact (Bialoskurski, Cox & Hayes, 1999; Nyström & Axelsson, 2002). Women are therefore unable to take up the parenting role they had anticipated and need to adjust to being a mother in the absence of their infant. In addition, early mother-infant interaction has important implications for psychological health of mothers as well as the ongoing relationship with their infant (Klaus, Kennell, & Klaus, 1995).

The milieu of parenting a premature infant in regional SCNs, within the broader context of motherhood in the twenty-first century, was of great interest to me as a midwife, mother and rural resident. Recognition of each family’s unique needs and providing individual care facilitates a positive experience for mothers (Wereszczak, Miles, &

Holditch-Davis, 1997) and reflects a model of family-centred care which is currently promoted, although not always practised, in most neonatal nurseries.

This study used an interpretive descriptive design that was informed by feminist postmodern theories. The strategy of in-depth interviewing was congruent to an interpretive descriptive methodology. In turn, both method and methodology complimented and reflected the values of a postmodern feminist framework. The inclusion of personal experience and understanding from reflective practice observations over many years, contributed to the methodology used in this study. My interest in this research stemmed from many years experience as a regional midwife, observing the 'comings and goings' of parents, predominantly mothers in SCN. As a mother myself, I recalled the intensity of the mother-baby relationship and wondered how these women coped with a clinical environment and ongoing separation. As a midwife, I was interested in the effect of the hospital environment on mothers' behaviour; I wondered just how it was for women trying to develop a relationship with a new member of their family, with whom they had limited contact in a clinical and relatively public area. In addition, mothers perceived by my colleagues as the most 'demanding' were the ones that largely piqued my interest because that is how I imagined myself in the same situation - scrutinising, slightly distrustful and reluctant to leave my baby with staff over which I had no choice or control. Unlike paediatric units, there are few opportunities for women to remain with their babies in neonatal nurseries.

Travelling was a dominant metaphor woven throughout the study, partly because as a rural resident, much of my own time is spent physically travelling. The women who agreed to participate in the study lived in western regional Victoria and were often some distance from their infant in SCN. During conversational interviews, I accompanied the participants through their nursery experience, as they 'navigated their way' through a confined area, congested with cots, rules and various personalities of staff and other families. Mothers with hospitalised infants traverse between two nurseries - a busy and controlled one in hospital and a silent, empty one at home. This journey took me geographically, down dirt roads, and emotionally to places I have never been. A feminist underpinning demands change to improve women's lives and it is through this research, nursery staff can develop an understanding of women's experiences and therefore assist mothers in their navigation of the nursery journey. Furthermore, as a midwife with a clinical background, I wanted to reconcile knowledge with the practice; aspiring towards a reduction in distance between myself and participants also extended to minimising the 'distance' between knowledge and practice.

Rural and regional aspects

In Australian literature, the terms rural, remote and regional are often used interchangeably but there are many aspects to consider when defining areas. The Australian Standard Geographical Classification Remoteness Areas classification has been used as the geographic basis for defining areas in recent government reports (Australian Institute of Health and Welfare [AIHW], 2006) and the main differences identified between rural and urban are long distances, inaccessibility to services & lower

population numbers (Smith, 2004). Participants recruited for this study were from areas classified as inner and outer regional Victoria, although slightly further west in Victoria are areas classified as remote (AIHW, 2006).

Pregnant women from regional and rural areas less than 32-34 weeks gestation are generally transferred to tertiary centres for birth, due to possible intensive care requirements of the infant (NHMRC, 2000). These specialist services are currently only available at larger hospitals in metropolitan areas. Transfers result in separation from family and dislocation from familiar supports. In Victoria, transfers to NICU may result in parents travelling several hundred kilometres from their home. Understandably, distance has been identified as a stressor in some NICU studies (Perehudoff, 1990) but not specifically in a regional/rural context and there is scant exploration of this topic in relation to mothers with hospitalised premature infants.

There is an increasing staff shortage of midwives in rural and regional areas, due to problems with recruitment and retention (Senate Community Affairs References Committee Secretariat [SCARCS], 2002). Nurses and midwives in these areas often provide a wide range of services with midwives working across the spectrum of maternity services, including neonatal care. SCN staff in regional areas are often multi-skilled midwives who rotate through all areas of a particular maternity department (Victorian Government Health Information, 2004), although this is partly dependent on the location of the nursery in relation to the ward. This may result in frequent staff turnover in the nursery and consequential lack of continuity of carer. Furthermore, variations and

contradictions in care as a result of multiple caregivers, have been identified as confusing for mothers in neonatal nurseries in a number of studies (Bialoskurski, Cox, & Wiggins, 2002; Hurst, 2001b). Rural midwives working in nurseries face potential problems of continuing education and maintaining current clinical practice (SCARCS, 2002); this may also exacerbate mothers' perception of inconsistent or incompetent care when premature infants are transferred back to regional centres from NICU.

In addition, mental health problems have been identified as higher in rural areas (Australian Institute of Health and Welfare [AIHW], 2003), although conflicting findings suggest more research is needed to explore the reasons beyond the rural-urban dichotomy (Fraser, Judd, Jackson, Murray, Humphreys, & Hodgins, 2002). However, maternal mental health problems may be aggravated by both the birth of a premature infant and residence in non-urban areas. Contributing factors in non-urban areas include lack of services, social isolation and fear of stigma (Fraser et al., 2002).

Study overview

This study aimed to reveal mothers' perspectives of their roles within the SCN and identify their needs in this environment. The purpose of this study was to deepen health care professionals understanding of mothers' interpretations of neonatal nursery environments. Insights into maternal perspectives could assist in providing improved outcomes for families of premature infants. The knowledge gained will provide insight to women's perspectives within the hierarchical institution of the hospital setting and assist

in the provision of care with a family-centred approach, reflective of midwifery practice. This study builds on the findings of previous research about mothers with hospitalised premature infants and provides further insight into women's perceptions of the nursery and their role within. It adds further knowledge to the small body of literature pertaining to SCNs in Australia. Finally, staff caring for premature infants in rural and regional areas, are predominantly multi-skilled midwives, but not exclusively. Hence, the term 'nurse' or 'nursery staff' is used throughout the study, with apologies to midwives who prefer their own title.

Eight women agreed to participate in this study and shared their experiences of SCN in two regional settings in western Victoria. Their stories related a range of challenging issues they experienced as they navigated their way to motherhood in the alien environment of the nursery. These women revealed how they juggled the many aspects of their lives while their infant was hospitalised. Their stories also revealed a complex set of concerns that the space of the nursery presented which impacted in many ways: physical restrictions and 'confinement'; mother-infant relationship; privacy; staff-parent relationships; and social interaction with other patients and visitors. Various difficulties were encountered by women in the confined space, which was shared with a socially diverse group of individuals- staff, families and visitors. Spatial aspects of the SCN environment were a major influence on women during their transition to becoming a mother. In addition, personal, family and geographical circumstances as well as medical problems resulted in some women adopting conflicting roles during the hospitalisation of their infant.

The thesis is presented in the remaining five chapters:

Chapter 2 examines the relevant literature to this study and identifies gaps in knowledge related to mothers' experiences of neonatal nurseries. A background of neonatal care orientates the reader to specific situations in Victoria, and major findings in previous neonatal studies will be critically examined. General discussion of maternal roles will converge to the relevance of the nursery setting on this role.

Chapter 3 describes and explains the theoretical and methodological approach to the study. Drawing on feminist and postmodernist theories, an interpretive descriptive methodology was developed. The relationship between feminism and motherhood is examined, and the methodology described, including method of data collection and analysis. The methodological congruence, together with my stance as researcher in relation to this topic, will also be argued.

Chapter 4 introduces the participants to the reader before presenting the findings divulged from in-depth interviews. Findings are presented within four intersecting themes: dislocated lives, space, nurse-mother interaction, and women's roles. Participants' voices are woven through the text to illustrate the meaning of their interpretation of the nursery environment.

Chapter 5 presents a discussion and analysis of predominant findings which are presented as sub-themes and compared to published literature. Although some issues correlate to

previous findings, other aspects such as participants' interaction with space within nurseries and the invisibility of roles other than a maternal one, represent new knowledge.

Chapter 6 concludes the thesis and discusses implications for clinical practice as a result of this study's findings. Recommendations for future research are made with a view to adding to Australian neonatal knowledge and further improving the care of families of premature infants.

Within the text of the thesis, participants' voices are presented as quotes in italics; quotes from other sources, to illustrate themes within each chapter, are presented in Arial font and single-spaced; and all others are within quotation marks. Several photos throughout the thesis illustrate the rurality of participants' homes compared to the foreign setting of a neonatal nursery.

In summary, premature birth is usually a traumatic event and the experience may be aggravated by residence in regional or rural areas. Professional involvement, personal observation and empathy for mothers of premature infants have driven me to explore the experiences of a small group of women in western regional Victoria. A qualitative approach underpinned by feminist principles helped to reveal these women's perceptions of their roles within two regional SCNs.

Chapter 2: Literature Review

> Parents should be treated as parents, not visitors (Carrier, 2004, p. 24).

A review of the literature pertaining to mothers of premature infants provides an overview of premature birth defining the implications and impact on families. While there is a considerable body of work relating mothering and parenting in the context of premature birth, the knowledge gains are limited. Few studies focus specifically on SCNs, with the majority using NICUs as the setting. Most studies exploring parental response to premature birth have used qualitative methodology with small samples, although several larger studies have taken a quantitative approach to measuring stress. Major findings identified in the literature, relating to mothers of hospitalised premature infants in the context of neonatal nurseries, are maternal distress, effect of separation, staff-mother relationship, family-centred care, the nursery environment and unmet expectations of the maternal role.

Background

Over the last two decades, medical advances in neonatal care have resulted in improved survival rates for extremely premature infants of less than 27 weeks gestation (Ward & Beachy, 2003). The result has been extended hospitalization of the infant and separation from parents (Flacking, Ewald, Nyqvist, & Starrin, 2006; Lau & Morse, 1998). A premature birth may result suddenly, leaving women ill-prepared for the abrupt transition to motherhood (Lupton & Fenwick, 2001). Stern (1998) referred to this transition as an

'accelerated metamorphosis' (p.1280). In general, the transition to parenthood is considered a stressful life event (Nelson, 2003); a premature birth compounds the effect. The birth of a premature infant represents a major crisis for mothers with the anticipation of a healthy infant replaced by a distressing array of emotions including shock, uncertainty, fear, guilt and grief (Boyd, 2004; Klaus et al., 1995; Wereszczak et al., 1997). Klaus et al. (1995) described the effect of premature birth on parents as having their '…lives disrupted, their biological rhythms in disarray…' (p. 132).

Prematurity is defined as gestation of less than 37 weeks gestation and exceeding 23 weeks, but most premature infants are born between 32 and 36 weeks gestation (Lumley, 2003). Premature births account for 6-10% of all births in developed countries (Lumley, 2003) and 6.9-7.9% in Australia (National Perinatal Statistics Unit, 2003). In 2003-2004, 7.8% of all births in Victoria were premature (Riley, Davey, & King, 2005) and nearly one quarter of these are from rural regions. According to statistics from the Victorian Perinatal Data Collection Unit (2004), the number of premature births in Victoria has fluctuated over the last decade, but generally indicated a slight increase with 4407 (1130 rural) births recorded in 1994 and 5057 (1245 rural) in 2003.

The increasing movement of later childbearing in Australia (Office of the Status of Women, 2004) has resulted in a trend of advanced maternal age and increasing use of reproductive technologies, both of which are associated with a higher incidence of premature birth (Tough, Newburn-Cook, Johnston, Svenson, Rose, & Belik, 2002). Premature birth is also associated with lower socioeconomic groups with the related

social and health problems, including drug use, extremes of maternal age, low education and lack of adequate health care (Ludlow, Evans, & Hulse, 2004; Peacock, Bland, & Anderson, 1995). Premature infants are susceptible to numerous medical complications as a result of their immature systems: respiratory problems, due to inadequate lung function; systemic infection due to reduced immunity; temperature instability due to high surface area: weight ratio and thin skin; and hypoglycaemia due to inadequate fat stores and metabolism (Goodwin, 2004; Noerr, 2004; Zukowsky, 2004). More severe complications such as necrotising enterocolitis (NEC) and intraventricular haemorrhage (IVH) often have long term effects requiring ongoing medical and social needs (Gracey, 2004). Respiratory complications such as bronchopulmonary dysplasia (BPD) may result in prolonged oxygen requirements following discharge (Zukowsky, 2004).

Hospitalization of a premature infant in Victoria is divided into three categories: Level 1 care, providing care for well infants at the mothers' bedside; Level II care or Special Care Nurseries (SCNs), providing intermediate care with nursery admission, investigation and monitoring; and Level III care or Neonatal Intensive Care Units (NICUs), offering life support with high dependency care including assisted mechanical ventilation, parenteral nutrition and specialised neonatal staff (NHMRC, 2000). In Victoria, the four tertiary Level III NICUs are situated in greater Melbourne with Level II SCNs situated in both regional/rural and metropolitan areas. There are 18 public SCNs and 15 private SCNs (Neonatal Emergency Transport Service [NETS], 2004). NICUs are confined to the metropolitan area because of facilities, staffing and appropriate medical back-up. As a result, all infants likely to require intensive care, including premature infants less than 32-

34 weeks gestation, are transferred to greater Melbourne, via the Newborn Emergency Transfer Service (NETS, 2004). Occasionally, an interstate transfer may be required if there are no available beds. Consequently, women may not see their infant for the first few days of life, or see them only briefly.

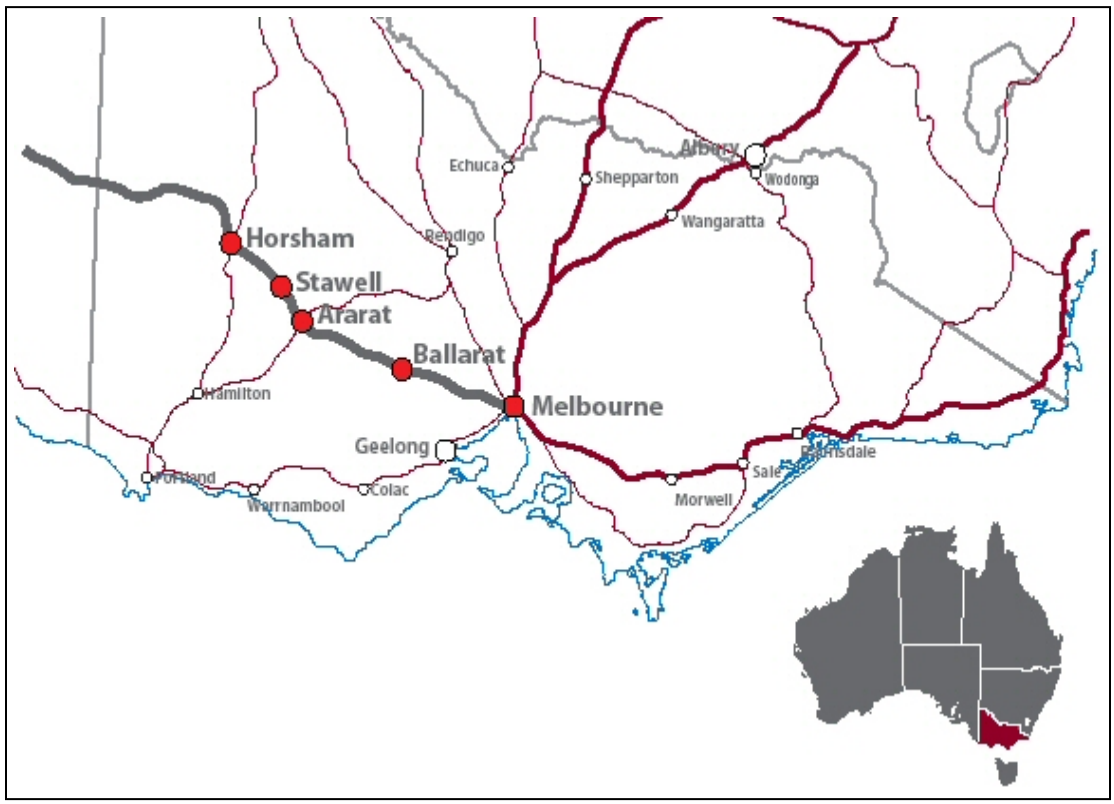

Figure 1. Map of western Victoria

Level II Special Care Nurseries

The terms NICU and SCN were used interchangeably throughout the literature (Gottfried, Hodgman, & Brown, 1984; Perehudoff, 1990; Walker, 1998), particularly when relating to facilities in other countries, but generally NICU was used to describe *all* nursery care for newborns. However, in Victoria, NICUs cater for very sick or extremely premature

infants and usually run on high bed occupancy; consequently, infants are transferred as soon as their medical condition is stable and intensive care is no longer required.

Level II nurseries in Victoria are sub-divided into ‘low-risk’ or low dependency, and ‘high-risk’ or high dependency (NETS, 2004), with the latter offering more intensive monitoring and care such as short-term ventilation prior to transfer to a NICU and in some institutions, nasal CPAP (continuous positive airways pressure). Nasal CPAP is a delivery method of positive pressure via nasal prongs, usually with oxygen, and unlike mechanical ventilation, has the advantage of not requiring intubation (NHMRC, 2000). The NETS Guidelines stated low dependency nurseries provide care for infants over 34 weeks gestation, who may require apnoea monitoring, intravenous therapy, phototherapy (for neonatal jaundice) and short term high oxygen requirements. High dependency level II nurseries may provide care for infants over 32 weeks gestation with higher oxygen requirements and possibly nasal CPAP, in addition to the care provided by low dependency nurseries (NETS, 2004; NHMRC, 2000). Therefore, depending on classification, level II SCNs deliver a high level of acute care which is decreased as the infant becomes more stable and matures.

Differences in hospital terminology, particularly in other countries, made it difficult for exclusive comparison of nurseries that provided the same level of care as SCNs in Victoria. For example, a study by Macnab, Beckett, Park, & Sheckter (1998) examining the effect of journal writing for mothers, referred to the ‘special care nursery’ in a tertiary care referral centre, but no further detail was provided. Other terms from North American

hospitals, presumably referring to SCNs, included ‘discharge nurseries’ (Klaus et al., 1995) and ‘newborn convalescent care units’ (Gottfried et al., 1984). An Australian study by Walker (1998) referred to NICUs or SCNs yet made no differentiation between the two areas in her study. Similarly, Heermann, Wilson & Wilhelm (2005) examining mothers in NICU, cited SCN research by Fenwick, Barclay, & Schmied (1999; 2001b) without acknowledgement of the different levels of nursery care. For the purpose of this research, unclear definitions in nursery terminology and the apparent amalgamation of NICU and SCN in many studies hindered the review of literature. However, the evident paucity of research pertaining exclusively to level II SCNs, particularly Australian, indicated a need for more research in this area.

Few studies compared NICUs with level II SCNs either from mothers’ perspectives or in specific detail. Environmentally, these settings differ with less technological monitoring of the infant, less intensive staffing ratios and fewer isolettes (Bruns et al., 1999; Lupton & Fenwick, 2001). Therefore, compared to NICU, SCNs have the potential for greater participation and involvement of parents, particularly mothers, who tend to spend a greater proportion of time in the nurseries than fathers (Franck & Spencer, 2003). The progress of the infant in SCNs is indicated by weight gain, gradual removal of various monitors and tubes, and transfer from isolette to open cot, often to a different area of the nursery (Lupton & Fenwick, 2001). This physical progression represents important physical milestones for infants as well as psychological ones for mothers as the infants approach discharge. The discharge criteria include temperature stability and consistent weight gain as a result of breast or bottle feeding (Gracey, 2004). Fenwick et al. (1999)

described the level II nursery as a period of ‘transition’ (p. 53) where the premature infant is physiologically stable and merely needs maturation before discharge home. In addition, mothers expect and are expected to participate more in care as infants progress to the ‘growing’ phase of their SCN stay and discharge planning becomes a reality, although some findings suggested parental activities were restricted by nursery staff (Fenwick et al., 1999). This ‘transfer of care’, from nursing staff to mothers, was examined by others (Bruns et al., 1999) where mothers were described as moving through a continuum from outsider to primary caregiver, albeit in a NICU setting. Thus, in a parenting context, as a transition to home and hence transition to fully adopting a maternal role, SCNs are a relatively unexplored area.

History

According to Lau and Morse (1998), the reactions and experiences of parents to premature birth have been studied since the 1960s. A large body of literature reported the negative impact on mothers of having a hospitalized premature baby and the major challenges that are faced (Affonso, Hurst, Mayberry, Haller, Yost, & Lynch, 1992; Hurst, 2001b; Meyer, Coll, Seifer, Ramos, Kilis & Oh, 1995; Pederson et al, 1987). Recurrent themes identified in the literature which were specific to mothers included: maternal concerns, the need for support, potential conflict with staff and the environmental impact of the neonatal nursery. Possible difficulties with attachment (Feldman, Weller, Leckman, Kuint, & Eidelman, 1999) and loss of maternal role (Costello & Chapman, 1998; Flacking et al., 2006) were also apparent. The resultant psychological distress and

possible development of postnatal depression (Davis, Edwards, Mohay & Wollin, 2003) may have negative consequences for the mother- infant relationship and long-term development of the infant (Klaus et al., 1995; Lau & Morse, 1998). In their historical overview of premature infants, Davis, Mohay & Edwards (2003) surmised that recent trends to fully involve parents in the care of their infants was simply returning to practices before the institutionalisation of these infants at the end of the nineteenth century.

Efforts to save premature infants gained momentum in France in the late 1800s, as a response to a devastated post-war population (Toubas & Nelson, 2002). Incubators (isolettes) were shown to improve survival rates but as neonatal care became increasingly institutionalized, parents were identified as possible sources of infection and consequently excluded from contact (Davis, et al., 2003). It was not until the 1960s, changes to obstetric practice supporting natural childbirth, extended from Europe to the United States (Klaus, et al., 1995); these changes included a greater acknowledgement of the family and its psychological well-being which remains evident in most units (Pederson, Bento, Chance, Evans, & Fox, 1987). As a consequence, there was increased parental involvement in care of the infant (Heermann et al., 2005). Hospital restrictions were gradually relaxed in the 1970s when a number of studies demonstrated no increase in infection rates when parental visiting was permitted (Klaus et al., 1995).

Consequently, neonatal units have undertaken specific interventions, including unrestricted visiting policies and encouragement of parental participation as ways to

enhance maternal attachment and support parents. These interventions benefit the mother-infant dyad in a number of ways, including: long-term psychological health of mothers and infants (Franck & Spencer, 2003), improved physiological outcomes to the premature infant as a result of increased parental contact (Davis et al., 2003) and greater confidence in the role of becoming a mother (Costello & Chapman, 1998). Many studies explored the responses of parents, predominantly mothers, to having an infant in NICU. Adopting the parenting role and associated difficulties within the environment was a common area of study (Fenwick et al., 2001b; Flacking et al., 2006; Scharer & Brooks, 1994; Wereszczak et al., 1997). Dominant issues identified in the literature have been thematically organised and will be discussed under the following headings: maternal distress, attachment and separation, nursery environment, nursery staff-mother interaction, family-centred care and unmet expectations of maternal roles. Generally, these themes are interconnected in the context of parenting in a nursery environment, with each one affecting another.

Themes

Maternal distress

A recurrent theme in the literature was mothers' fear of adverse infant outcomes, with death an over-riding concern (Hurst, 2001b; Pederson et al., 1987; Wereszczak et al., 1997). However, conflicting findings on the relationship between maternal psychological distress and the severity of premature infants' illness suggested causes of distress are multi-factorial (Meyer et al., 1995; Nyström & Axelsson, 2002; Pederson et al., 1987)

and related to other factors. These included a mother's personality, her understanding of the situation, financial concerns and resources, all of which may influence her response to the hospitalization of the infant (Logson & Davis, 1998).

Different studies have identified various sources of stress to mothers of premature infants, some suggesting separation from the infant, insufficient family support and maternal adjustment remained significant stressors to mothers (Affonso et al., 1992; Wereszczak et al., 1997). Feelings related to separation may be exacerbated by distance and unfamiliar surroundings in the event of the infant requiring transfer to a larger hospital for more intensive levels of care (Affonso et al., 1992). Parents are likely to be dislocated from family, friends and other sources of support in these circumstances. The enforced separation from their infants when women are discharged from hospital may aggravate their concern for their infants' survival (Klaus et al., 1995) and their inability to participate in the care may result in feelings of helplessness (Fenwick et al., 2001b).

Competence of nursery staff and good communication were identified by mothers as facilitating a positive experience with hospitalized premature infants (Bialoskurski, et al., 2002; Holditch-Davis & Miles, 2000). In addition, Cescutti-Butler and Galvin (2003) identified competency as not only practical nursing skills but also as caring behaviour. Trust in the ability of the infant's carer was paramount to the emotional well-being of mothers (Boyd, 2004; Holditch-Davis & Miles, 2000). It could be surmised that the mother of a premature infant in a Level II SCN may have a reduced sense of fear of her infant's death, and her preoccupations differ as her infant approaches discharge, although

Pederson et al. (1987) identified nearly one quarter of mothers of *well* premature infants expressed concern about the infants' survival, a finding supported by others (Nystrom & Axelsson, 2002). Boyd (2004) suggested mothers fearing a relapse of their infant's condition in SCN may be even more anxious.

The information needs of mothers in NICU may differ considerably with the infant's medical stabilization and transfer to a SCN. The desire for technical knowledge and the status of the infant's medical condition, described by Hurst (2001a) may be replaced by information needs focussed on less medically related aspects such as temperature stability and feeding routines. Research specific to SCN indicated mothers sought to learn nursery routines and adapt to nurses' expectations of 'nursery behaviour' as a means of accessing their infant (Fenwick, Barclay, & Schmied, 2002). However, ongoing communication in regard to the infant's condition and progress was seen as essential to most mothers; the quantity and type of information received may influence the parental perception of the infant's health status (Catlett, Miles, & Holditch-Davis, 1994). Wereszczak et al. (1997) described mothers' 'normalising' their premature infants by handling and dressing them as well as becoming familiar with specific infant cues. Likewise, their infant's growth and consequent removal of technical equipment over the ensuing weeks indicated a gradual independence from medical support (Lupton & Fenwick, 2001; Wereszczak et al., 1997).

A mother of a premature infant who has been transferred from a NICU to a SCN may have different expectations of the environment and her role as caregiver. The less

technological surroundings combined with the medical stabilization of her infant may lend itself to a parental supposition of greater levels of involvement. A significant gap exists in neonatal nursery literature exploring the specific phenomenon of mothers' adaptation to SCNs following their infant's transfer from NICU. Mothers are understandably distressed following a premature birth and ongoing hospitalisation of their infant. However, stressors may change over time and in different environments (Affonso et al., 1992).

Clearly, the experience of having a hospitalised premature infant is traumatic. Uncertainty of infant outcomes, an unfamiliar environment and inability to fully care for their infant was distressing for mothers. Separation from the infant is inevitable following a premature birth, and has been described as one of the worst aspects to having a hospitalised infant (Nyström & Axelsson, 2002). The impact of separation on attachment is discussed under the next theme.

Attachment and Separation

> No one mentions the strangeness of attraction - to a being so tiny, so dependent, so folded-in to itself - who is, and yet is not, part of oneself (Rich, 1976, p. 36).

Attachment, defined as an enduring affective bond (Colin, 1996), has been the subject of intensive investigation since the late 1950s when the theory of the child's attachment to its mother was defined by Bowlby (1958). Criticisms of this theory include difficulty in a clear definition as the term incorporates many aspects and evokes different meanings,

including specific behaviours and endurance of the relationship (Colin, 1996). Inadequacy of definition was evident and some literature reported confusion with the concepts of love, connection and instinct (Bialoskurski, et al., 1999). Klaus et al. (1995) provided some clarification to the terminology, defining 'attachment as the tie from infant to parent' and 'bonding as the tie from parent to infant' (p. xviii), yet conceded that a universal definition of attachment is the emotions securing one individual to another. In the context of motherhood, Kitzinger (1992) described attachment as a 'fierce tenderness…and all the most intense emotions.' (p. 15). More specifically to mothers with hospitalised infants, Bialoskurski et al. (1999) examined the nature of attachment in NICU and argued that it was an individualised process, dependent on variable factors.

According to Boyd (2004), the importance of physical contact was promoted by Budin in 1907, and the relationship to attachment has been supported by subsequent studies of mothers and infants (Bialoskurski et al., 1999; Colin, 1996). Some researchers hypothesized the attachment process begins before birth and a range of psychological, physiological and behavioural responses, including touch and nursing, may be responsible in directing a mother to maintain her physical and emotional proximity to her child (Klaus et al., 1995). The reality of a premature infant and the associated institutional support may be the antithesis to a mother's image of the 'ideal' infant. However, many investigations indicated the interaction between a mother and her preterm infant are impeded by the associated separation, consequently disrupting the attachment process (Affonso et al., 1992; Bialoskurski et al., 1999; Nyström & Axelsson, 2002). Findings from an Australian study by Rowe, Gardner and Gardner (2005), revealed parents

differentiated between their own ‘nurturing’ touch which represented attachment, and ‘nursing’ touch by staff. Within the context of motherhood, women may find themselves in a state of ‘primary maternal preoccupation’, (Kitzinger, 1992, p. 11, citing Winnicott, 1965), which is disrupted by separation when the infant is hospitalised. Frequent contact and tending to infants’ needs are basic, yet anticipated, elements of parenting and parents of premature infants are generally deprived of these early experiences due to ongoing hospitalisation of their infant. Early contact greatly facilitates the attachment process for the mother of a premature infant and skin-to-skin care, otherwise known as kangaroo care (Klaus et al., 1995) has demonstrated physical and psychological benefits to both mother and infant (Carrier, 2004).

Studies reported that the physical appearance of premature infants caused much parental concern (Affonso et al., 1992; Klaus et al., 1995) often with negative effects on attachment. Many parents experienced shock at the first sight of their premature infant; one mother described her infant ‘like that bird that had fallen out of the nest’ (Holditch-Davis & Miles, 2000, p. 16). Klaus et al. (1995) stated mothers perceived their premature infants as ‘unfinished’ and ‘fragile’ (p. 132) and Wereszczak et al. (1997) reported a maternal reluctance to attach due to fear of infant death and impending loss, a finding confirmed by others (Feldman et al., 1999). This initial reaction, combined with other factors, has been implicated in subsequent attachment difficulties (Perehudoff, 1990). Nystrom and Axelsson (2002), exploring the experience of infant separation on mothers, identified themes of ‘being an outsider, lack of control and caring’ (p. 279); other studies revealed similar findings with women describing feelings of powerlessness, isolation and

an inability to fulfil a maternal role (Holditch-Davis & Miles, 2000; Hurst, 2001). Furthermore, an emerging body of evidence indicates that premature infants have different responses compared to full-term infants, with increased disorganized behaviour, which is often extremely difficult to interpret by mothers (Davis, Edwards, & Mohay, 2003; McCain, 1990). High levels of maternal distress may be inversely related to less optimal mother-infant relationships leading to the possible development of ongoing parenting problems (Perehudoff, 1990).

Hence, published literature suggested attachment difficulties may be exacerbated when an infant is born prematurely. Parental concern regarding the appearance and survival of the infant, ongoing separation and an infant who may be difficult to parent, may have profound and long-term effects on attachment. Separation also impacts on the developing maternal role due to inadequate access and limited contact, with parents reliant on staff for information. Nursery staff are in an ideal position to facilitate parents' access to their infants (Bruns et al., 1999; Lupton & Fenwick, 2001); likewise, several authors claimed it was mainly through nurse-mother negotiations that parents gained this access (Fenwick et al., 2001b, 2002; Hurst, 2001a). This relationship will be examined in the following section.

Nursery staff-mother relationships

> Most women have been mothers in the sense of tenders and carers for the young… (Rich, 1976, p. 12)

Interaction between nursery staff and mothers was a predominant theme in neonatal literature, describing either staff's or mothers' perspectives, with most studies reporting a combination of interactions, both positive and negative. Published research pertaining to mother-nurse relationships mainly referred to NICU, but findings from the SCN setting concurred on many levels (Fenwick et al., 2001b; Hurst, 2001a). Nystrom and Axelsson (2002) argued the dyadic mother-infant relationship needed to adjust to accommodate the presence of the neonatal nurse. However, findings from a variety of studies indicated the relationship between neonatal nurses (or midwives) and mothers in nursery settings is often discordant (Heermann et al., 2005; Holditch-Davis & Miles, 2000; Hurst, 2001a; Rowe et al., 2005; Scharer & Brooks, 1994), and discrepancies between parent perceptions and nursing staff expectations were often identified. Nurse-mother interactions impacted on mothers' developing relationships with their infants; mothers identified nurse expertise as a barrier to a partnership in the care of their infant (Heermann et al., 2005) resulting in women feeling 'inconsequential' (Fenwick et al., 2001b). Hurst's (2001a) ethnographic work reported mothers felt their behaviour and actions were frequently misinterpreted by nursing staff which increased mothers' anxiety and feelings of powerlessness. Findings from a number of investigations revealed little understanding by staff of mothers' needs (Fenwick et al., 2001b; Hurst, 2001b; Wereszczak et al., 1997), and Scharer and Brooks (1994) described some nurse-mother

relationships in NICU as ‘competitive and conflictual’ (p. 45) as both parties contended for control of the infant.

The literature clearly indicates varying degrees of staff-mother conflict, with a dominant role by staff and lack of a collaborative partnership between staff and mothers. A collaborative partnership with nursery staff where parents were involved in decision-making and advocacy for their infant, may have assisted mothers in feeling less like visitors and more like primary caregivers (Flacking et al., 2006). Reports of multiple caregivers and inconsistent information (Bialoskurski et al., 2002; Hurst, 2001a) presented further barriers to partnerships with staff. Attempts at forming partnerships were often thwarted when mothers sought to develop a relationship with staff, a relationship referred to by Hurst (2001b) as a ‘guarded alliance’ (p. 55) rather than a partnership. Some mothers believed if they were perceived as ‘difficult’ or demanding, the nursing care towards their infant may be compromised (Fenwick et al., 2002) and they expended considerable emotional energy to develop good relationships with nursery staff (Hurst, 2001b); mother-nurse relationships such as these were unlikely to promote good communication and trust. Hence, nursing staff were seen as a clear link to infant access by mothers who wished to work collaboratively with staff, yet the nature of nurse-mother relationships described in the literature indicates unresolved tensions.

In Level II SCNs, where less acute levels of professional care are required, nursery staff were also perceived by mothers as more dominant in maintaining the role of primary caregivers (Fenwick et al., 1999; Wilson, McCormack, & Ives, 2005), suggesting some

staff continued to resist parental involvement, consequently not meeting mothers' needs. Hurst (2001b) argued the primary role maintained by staff was facilitated by their expert knowledge of both premature infants and the institutional policies and procedures. The inability of mothers to assume a more active role as a result of staff acting as 'gatekeepers', (Lupton & Fenwick, 2001, p. 1014), was unlikely to benefit their preparation for the impending infant discharge, yet active involvement by parents has been shown to greatly assist the transition home, in terms of confidence and familiarity with their infant (Gracey, 2004).

Therefore in published literature, predominantly from mothers' perspectives, there were some tensions with nursery staff regarding authority and ownership of infants which in turn, affected mothers' parental participation and caregiving. Asymmetrical communication with staff and ambivalence regarding the parental role by staff did little to empower women as mothers. Nursery staff have been implicated as having a key role in the development of family-centred care, yet it was evident that the adoption of a collaborative partnership through a family-centred model has been met with some resistance (Bialoskurski et al., 2002; Wilson et al., 2005). The concept of family-centred care (FCC) in the nursery setting will be discussed under the next heading.

Family-Centred Care (FCC)

Family-centred care (FCC) in a nursery context recognises the parents as primary caregivers and responsible advocates for their hospitalised infants (MacKean, Thurston,

& Scott, 2005) and despite varying definitions, the philosophy of FCC acknowledges and respects the essential role of families during their child's hospitalisation (Bruns et al., 1999). Family members are encouraged to participate in care and decision making and encouraged to form supportive relationships with staff (MacKean, et al., 2005; Peterson, Cohen, & Parsons, 2004). More recently, there has been an increasing interest in the role played by the family in the development and care of premature infants, with benefits evident to infants as well as parents. Research has supported the benefits of FCC including improved parental satisfaction, better communication between parents and staff, and greater confidence in infant care (Bowie, Hall, Faulkner, & Anderson, 2003; Bruns et al., 1999).

Nursing staff that provided more individual care and recognized each family as a unique unit increased the likelihood of providing a positive experience for mothers (Wereszczak et al, 1997; Heermann et al., 2005). For example, Klaus et al. (1995) suggested nursery staff could acknowledge the importance mothers placed on procedures which they perceived as major milestones, and not just routine events [nurses' perception], such as the infant progressing from isolette to open cot. This understanding of 'little things that matter' (p. 186) supports the philosophy of FCC and was highlighted in Gasquoine's phenomenological study (2005) of women with hospitalised children.

However, despite an increasing body of evidence describing the advantages of FCC within neonatal nurseries (Evans & Philbin, 2000; Hurst, 2001b), literature indicated a significant discrepancy between practice and recommendations, mainly due to difficulty

in the development of a parent-staff partnership in care (Fenwick et al., 1999; Hurst, 2001a; MacKean et al., 2005). Although staff recognised the importance of FCC, they displayed ongoing resistance to its implementation in neonatal nurseries (Bruns et al., 1999; Fenwick et al., 2001b), resulting in an inconsistent approach to care (Wilson et al., 2005). Inconsistent care also resulted from multiple caregivers and was confusing for women, making it difficult to obtain reliable information regarding their infants (Hurst, 2001b).

Mothers clearly needed emotional, social and practical support to enhance their role as partner in a FCC model of care. Nursing staff required understanding and recognition of specific parental needs to fully implement FCC into their practice (Bialoskurski et al., 2002). Carrier (2004) claimed parents of premature infants required ongoing emotional support and acknowledgement of the importance of their relationship with their infant. Social support after premature birth was identified as beneficial in the adjustment to parenthood (Scharer & Brooks, 1994), and strongly associated with a sense of well-being (Logson & Davis, 1998). Extraneous stressors such as distance to the hospital, family conflict or financial issues compounded difficulties in parenting adjustment, but practical support alleviated some stress (Logson & Davis, 1998; Perehudoff, 1990).

Thus, it is evident that FCC promotes parental involvement in the nursery setting, although difficulties in implementing the practise are still prevalent. In addition, an important component of FCC was numerous forms of support from staff and family members. Despite the adoption of varying degrees of FCC policies to many nurseries,

mothers' perceptions of the environment continued to reflect a visitor status. Klaus et al. (1995) referred to the mother being 'invited' into the nursery as hospitals adopted a FCC approach in the 1970s; current literature from mothers' perspectives, indicated this interpretation is still fundamental. Women's sense of intrusion into the nursery was persistent throughout current literature (Flacking et al., 2006; Heermann et al., 2005) with many women feeling as 'outsiders' (Nyström & Axelsson, 2002, p. 277). It was apparent both staff and the environment played a part. The following review on the nursery environment places FCC within the context of this setting.

Environment

Traditional nursery layouts in Western hospitals are large open rooms with the nursing workstation in the same room as the cots, for ease of observation (Evans & Philbin, 2000). Few studies described actual physical characteristics of their nursery settings, although Lupton & Fenwick (2001) and Bruns et al. (1999) gave a detailed description of a NICU environment, with tiny infants attached to beeping machines and lying in perspex boxes with tubes in their noses and mouths. The relocation to SCN areas included transfer from isolette to open cot, where infants were 'attached to fewer and fewer machines and often moved around the nursery in a predetermined fashion' (Lupton & Fenwick, 2001, p. 1014). Correspondingly, Bruns et al. (1999) indicated how the physical layout of the nursery reflected an infant's medical condition with sicker infants placed near the front of the unit. A recent description of an Australian SCN, portrayed a brightly lit, cramped and noisy area (Wilson et al., 2005). The inevitability of noise, chaos and lack of privacy in neonatal nurseries as a result of design and equipment, was evident in other literature

(Perehudoff, 1990; Hurst, 2001) and presented mothers with a further impediment to parenting. Some mothers reported the noise factor to be their most significant stressor in the NICU environment (Wereszczak et al, 1997). The increasing evidence related to detrimental effects on infants from light and noise factors, has resulted in some nurseries addressing the issues by refurbishment and/or changes to practice, both locally and overseas (Evans & Philbin, 2000; RWH, 2004).

With the need for vigilant surveillance of infants, staff are constantly present in the neonatal nursery which is often designed with accessible observation a priority from all vantage points. A consequence of this design is little privacy for mothers. The analogy of a 'fishbowl' used by Klaus et al. (1995, pp.153-4), in relation to lack of privacy and the negative effect on attachment, matched mothers' interpretations (Scharer & Brooks, 1994); likewise Boyd (2004) described the difficulty of having to 'parent in public' (p. 83). Thus, the nursery can be considered as an environment of 'exposure': the infant is exposed for required observation and monitoring; the mother is exposed in her vulnerable state (Hurst, 2001) and the neonatal staff are exposed to possible scrutiny by the mother as she often has little to do but 'sit and watch' (Fenwick et al, 2001b, p.59). Despite the differences in environment, there were similarities in parental responses to both NICU and SCN with both settings interpreted as medicalised and task-orientated areas (Fenwick et al., 1999; Walker, 1998).

SCNs are situated within acute care hospital settings and the environment may be strange and unfamiliar to parents (Gottfried et al., 1984; Meyer et al., 1995). The 'prescribed

hierarchy of authority' (p. 207) of the hospital setting, is maintained with rules, regulations and administrative practices (Cockerham, 1986). By their hierarchical nature, hospitals adopt an authoritarian stance (Short, Sharman, & Speedy, 1993); the neonatal nursery has been portrayed as also adopting an authoritarian stance with its inflexible routines and rules (Fenwick et al., 2002; Wilson et al., 2005). An Australian investigation of the nursing culture in SCNs, indicated a 'manipulative and controlling' environment (Walker, 1998, p. 90) where staff engage in an 'authoritative, autocratic style of decision making' (Wilson et al., 2005, p. 32), which clearly inhibits the role of mothers. In addition, the confined physical space of a neonatal nursery lends itself to intensity of relationships between staff and mothers, with the potential for conflict and struggle for control over caregiving roles (Fenwick et al., 1999).

It is evident from the literature that the nursery environment impacted on women's maternal role as they attempted to care for their infant. Hurst, (2001a) described mothers as 'sophisticated analysts and courageous strategists' (p. 55) in their attempts to adapt to mothering in the nursery environment. Mothers of premature infants identified lack of privacy as a major issue, impacting on parental interactions (Bialoskurski et al., 2002; Hurst, 2001a), yet this seemed unavoidable given the nursery design. Privacy, defined as the 'opposite of public exposure' (p.79) in a nursery setting, was important for women and associated with reclaiming the role of mother (Flacking et al., 2006). The maternal role within the nursery context will be discussed next.

Unmet expectations of maternal roles

Premature birth results in altered expectations including that of maternal role. Maternal identity is a complex concept and develops as a result of social, cultural and emotional elements as well as reciprocal interaction with the infant (Flacking et al., 2006; Kitzinger, 1992; Mercer, 2004). Many psychological concepts of motherhood and mothering focussed on the mother as principal caregiver, with little consideration for the meaning of motherhood for women (Phoenix & Woollett, 1991). Ongoing scholarly debate is evident with recent suggestions that 'maternal role attainment' (MRA), be replaced by the term 'becoming a mother' (BAM) as the static inference of the first term does little to reflect an evolving and 'dynamic transformation' (Mercer, 2004, p. 226), which is ongoing and 'never completed' (Kitzinger, 1992, p. 204). In contrast, some studies exploring the development of the maternal role in a neonatal nursery setting identified stages of evolving as a mother. Bruns et al. (1999) identified four progressive stages, culminating in the category of 'mother as expert and worrier', which reflected the tension between familiarity with the infant in the hospital setting and the anxiety directed towards pending discharge.

Traditional stereotypes of women within families persist, with high expectations of 'mothering characteristics' (p.164) despite societal change and shifting values in Australia (Richards, 1997). Specific expectations of mothers' behaviour and visitation by nursery staff (Fenwick et al., 1999) correlated with these broader societal expectations of women. Social constructions of a 'good mother' may be synonymous with 'normal' motherhood, (Phoenix & Woollett, 1991); a mother may feel unlikely to fit this particular

mould if she is separated from a child who is premature. ‘Nursery mother’ was a term applied to mothers of hospitalised infants by staff (Lupton & Fenwick, 2001, p. 1012), and a ‘good’ nursery mother was ‘friendly, sensible and interested’ (Fenwick et al., 2001b, p. 57) as well as caring and attentive (Scharer & Brooks, 1994). Attitudes by nursery staff, sometimes perceived by mothers as judgmental, indicated the strict criteria in which staff expected mothers to conform (Lupton & Fenwick, 2001; Scharer & Brooks, 1994).

Significant adjustment problems may occur during the transition to motherhood, particularly with a difficult postnatal recovery or infant admission to the nursery (Nelson, 2003) and women with premature infants experience an early and unexpected transition. Literature referred to the ‘loss’ of the parental role (Klaus et al., 1995; Perehudoff, 1990); however, for a woman who has suddenly become a mother prematurely, difficulty in adoption of the parental role was a more pertinent description (Boyd, 2004; Stern, 1998). Similarly Perehudoff (1990), referred to ‘alteration’ of the parental role (p. 41), inferring rather than being ‘lost’, the role was unable to be fully assumed. Therefore, the role may be partially retained with the redistribution of infant care to nursery staff and some mothers referred to sharing the parental role with staff (Holditch-Davis & Miles, 2000), although difficulties in this relationship are apparent and have been previously discussed. The *anticipated* role of motherhood transformed into a loss with the arrival of a premature infant and its ensuing hospitalization. Furthermore, the needs of any new role cannot be wholly anticipated, particularly motherhood, and more so in the event of a premature birth (Logsdon & Davis, 1998).

Impediments to maternal role development have been major stressors for women and are exacerbated by difficulties in negotiating a caregiving role with staff (Fenwick et al., 2001b; Wereszczak et al., 1997). Mothers and staff reportedly had difficulty in determining their own roles (Walker, 1998) as both shared concern and responsibility to the infant (Rowe et al., 2005; Wilson et al., 2005) who has not been fully assimilated into its family due to separation (Bruns et al., 1999). Therefore, women with hospitalised infants may have to assume an 'institutional role' (Cockerham, 1986, p. 217), with dependence on staff and minimal decision making regarding their infant. Several researchers referred to the difficulty of sustaining an intense relationship with staff over a prolonged period where emotions were suppressed to maintain an environment of civility (Hurst, 2001b; Lupton & Fenwick, 2001; Scharer & Brooks, 1994). Uncertainty related to maternal role was also identified as a major problem facing mothers of premature infants, particularly in regard to taking their infants home. Lack of confidence and feeling unprepared for discharge was correlated with difficulty in attachment (Costello & Chapman 1998). Not surprisingly, women participating in a programme in which they roomed-in for 48 hours and took full responsibility for their premature infant felt better prepared for independent parenting and the transition home (Bruns et al., 1999; Costello & Chapman, 1998).

Most neonatal studies explored the maternal role to the exclusion of other roles. Interestingly, women in a study by Fenwick, Barclay, & Schmied (2001a) valued nursing staff who discussed things 'rather than just babies' (p. 587) suggesting they enjoyed being recognised beyond a nursery mother role, as well as sharing interactions with staff in this

manner. Expectations of a maternal role in the nursery correlated to societal expectations of mothers but with more strict criteria. Difficulties in adjustment to this role were compounded by the need to maintain mothering as a social role in the nursery, and many studies suggested women perceived their maternal role in the nursery as a subordinate one.

Conclusion

In summary, the literature clearly indicates the experience of having a hospitalised premature infant is stressful and places parents under enormous strain. The unique circumstances surrounding premature birth impact on women in many ways. Premature birth is often unexpected, traumatic and associated with medical complications. Following birth, mothers are preoccupied with their new infant with whom they can only develop a partial relationship. Concern for the infant's well-being, possible conflict with staff, separation, the nursery environment and unmet expectations of their anticipated maternal role are outstanding findings from the literature.

Research has been predominantly undertaken in North America and the United Kingdom. This literature review has demonstrated that studies on mothers of premature infants are mainly confined to NICUs, with little exploration specific to the different setting of SCNs, and minimal research in the Australian setting. It is highly relevant to this study that minimal research has focussed exclusively on SCN or the roles of women beyond the maternal one, and it is this gap which calls for further knowledge and implies a need to

study the experiences of women with infants hospitalised in SCNs, including regional areas. Current literature examines many aspects of the adjustment to a maternal role within the nursery context, yet there is a definite paucity in the knowledge around mothers' other roles in this setting, or if they do in fact have other roles. A postmodern feminist influence on this current study allowed for the multiplicity of women's understanding of family life, parenting and caregiving (Baber & Allen, 1992), and thus, aimed to discover other roles women may adopt throughout their experience in the nursery setting. The next chapter explores and justifies the theoretical and methodological approach used in this study.

Chapter 3: Methodology

As a researcher influenced by feminist principles, I sought an approach to best explore the multiplicity of women's roles in a specific setting. A perspective located within postmodern feminist theories provided a suitable background for this exploration as well as sitting comfortably with my own feminist beliefs. This study utilised a qualitative approach that incorporates the subjective and interpretive as 'truth' (Morse & Richards, 2002, p. 167). Women's reality as mothers is diverse and hence the diversity of qualitative methodologies best reflects these differences (Gilgun, Daly, & Handel, 1992, p. 27). Postmodern feminist theories complemented an analysis using interpretive description. Interpretive description recognises the 'constructed and contextual nature of human experience' (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 5) including multiple realities and acknowledgement of the individual. This methodology was selected to assist my discovery of the complexity of women's roles through women's own narratives of their experiences. The first section outlines the suitability and relevance of a feminist approach. Subsequent sections detail interpretive description, method of data collection, ethical issues and analysis of findings.

Feminist theory

> A postmodern feminist approach allows us …to take a point of view without claiming to speak for all women (Baber & Allen, 1992, p. 12)

In asking the question, 'How do women with hospitalised premature infants perceive their roles within regional special care nurseries?' I wanted to uncover the feelings and meaning behind women's perceptions of their experiences with SCN. 'Looking at the world through women's eyes' (Reinharz, 1992, p. 248) is considered a central theme of feminist research and is pertinent to this study in which women participants and their experiences play a central role. The main feminist principles informing this research were 1) exploitation and oppression of women occurs, particularly within the family context; 2) women's experiences are recognized as meaningful and important; and 3) empowerment of women is required to bring about change (Baber & Allen, 1992; Reinharz, 1992). Through a feminist perspective, women's personal experiences and the validity of their perceptions as 'truth' are recognised; these complexities will deepen the understanding of women's situations (Stanley & Wise, 1993; Humm, 1995). Feminist theories and research are concerned with the central idea of women's equality with men and identifying and addressing the reasons this doesn't occur. Closely linked to inequality is the issue of women's oppression.

A feminist perspective acknowledges the existence of women's oppression and seeks to understand those oppressive forces (Harding, 1991; Baber & Allen, 1992). Humm (1995) defines oppression as male domination and authority over women, claiming some feminists believe women's role of motherhood is a primary cause. Oppression and subordination of women occurs within many settings: economic, biological, cultural, material and psychological with oppression inextricably linked to the institutionalisation of being a woman (Rich, 1976). The hidden burden and devaluation of domestic work

and childcare, also considered oppressive aspects of family life (Baber & Allen, 1992; Maushart, 2005) are compounded by the other roles women adopt in the 21st century. However, the definition and meaning of oppression differs among feminist scholarship. Some feminists believed oppression to be an 'unclear and analytically unusable concept' (Curthoys, 1988, p. 73) and despite a universal opposition, feminists differ in their beliefs of what represents oppression (Humm, 1995). Tong (1998) claimed women's oppression was a framework for other types of domination, for example the oppression of consumers of the health system (Alvesson & Sköldberg, 2000) and literature related to hospitals and more specifically, neonatal units indicates oppression of individuals continues to occur within these settings (Bialoskurski et al., 2002; Hart, 1985).

Variations of feminist theory resulted in a range of classifications (Harding, 1991; White & Klein, 2002), and many different perspectives and frameworks have developed within the wide range of feminist thought (Tong, 1998). Hence, feminism is now characterised by great diversity and a plurality of approaches (White & Klein, 2002; Herrmann & Stewart, 2001). Multiple meanings attributed to feminist thought (Harding, 1991), expand and complement the multiple realities of postmodernism. The main premise of postmodernism is that no final or absolute truth exists (Ezzy, 2002).

My research was informed by a postmodern, feminist perspective (Zalewski, 2000). Some feminist theories have been criticised for their apparent 'essentialism' which ignores differences among women and makes generalised claims about all women, thereby contradicting the essence of feminist thought. However, postmodernist approaches

deconstruct essentialism with a view of understanding women through plurality and difference (Baber & Allen, 1992; Zalewski, 2000). This exploration of women's perceptions is gender-focussed but not confined to gender. Women's experiences are dependent on age, class, family status and other factors (Baber & Allen, 1992; Tong, 1998) and gender intersects with these. In addition, a focus confined to gender may repress multiple aspects of an individual (Caine & Pringle, 1995) and each individual plays various roles across different situations (Alvesson & Sköldberg, 2000). Diversity among women includes differences among mothers and their attitudes to caregiving (Baber & Allen, 1992).

Within the nursery, I sought to understand participants' perspectives as individuals, health consumers, mothers and women. Postmodern feminists' belief in many truths supports the promotion of diverse characteristics of each woman's identity (Zalewski, 2000) and assisted in this exploration through women's interpretation of their roles within the SCN environment. The women in this study shared commonalities of experience by having a hospitalised premature infant but their stories epitomised diversity by their family situations and responses to a SCN environment.

Feminism and motherhood

> You will lose your temper, feel guilty, suffer from anxiety, long for solitude…and even occasionally feel like running away (Fedler, 2006, p. 25).

Fedler's description of maternal reactions from an article on motherhood in a recent Australian weekend newspaper magazine, was labelled 'parenting accessories' and

illustrates a deconstruction of romanticised motherhood in the media. The romantic ideology includes mothers' unconditional nurturing of their children and personal fulfilment through total devotion to the family (Phoenix & Woollett, 1991; Rothman, 1991). However, this unrealistic notion of motherhood is vastly different to the practical work of the role and also excludes women's needs. The overlapping ideas of 'woman' and 'mother' (McNay, 1992, p. 96) and continuing identification of women with motherhood are deeply entrenched in Western societies but recent publications, including media reports referred to the persistent disjuncture between feminism and the multi-faceted dimensions of motherhood (Fedler, 2006; Legge, 2005; Wilson, 2005). The principles of an 'ideal' mother continue` to be alternately dismantled and affirmed through the media.

Theories developed in the 1960s and 1970s, explained the transition to motherhood with women expected to *achieve* a particular maternal role, however, women's own perspectives were examined more thoroughly in feminist and sociological work (Rich, 1976; Rogan, Schmied, Barclay, Everitt, & Wyllie, 1997). Motherhood has triggered broad debate and polarity among feminists, consequently alienating some women from feminism, women who supposedly were the beneficiaries of the movement (Somerville, 2000; Tong, 1998). Some feminists associated mothering with servitude (Rich, 1976; Tong, 1998) and others believed motherhood was a 'handicap to be overcome' (p. 257), in order to gain equality (Lake, 1999). Rhetorical debate ensued as to whether motherhood was a socially and culturally constructed role or a biological predisposition (Tong, 1998), with a theoretical differentiation between the social *institution* of

motherhood under patriarchy and women's subjective *experience* of motherhood (Rich, 1976). Although there is ongoing debate regarding the biological predisposition of women, the complexities of a mothering role are probably best summed up by Rothman (1991), 'motherhood is a biological relationship in a social context and a social relationship in a biological context' (p. 208).

Motherhood affects women's lives and therefore, as one of 'women's issues' (p. 191), becomes inextricably linked to feminist theory (Pateman & Gross, 1986). However, there is difficulty locating motherhood within feminist discourses. Thirty years ago, motherhood was considered a 'crucial, still relatively unexplored, area for feminist theory' (Rich, 1976, p. 15); some feminists are still uncomfortable with this juxtaposition of motherhood and feminism (Tong, 1998). Likewise, Burns (1994) claimed that 'theorising the positive aspects of motherhood, has not been a strong strand in feminist thinking' (p. 278) with motherhood strongly associated with oppression, conflict and contradictions (Phoenix & Woollett, 1991; Tong, 1998). Indeed, I found many indexes in feminist books devoid of 'motherhood' and believed feminism and motherhood to be almost irreconcilable. This absence inferred motherhood was a marginal topic and not worthy of feminist analysis. However, more recently, some feminists have 'rehabilitated' the family (Somerville, 2000) and an anti-family sentiment has been replaced with a reconstruction of the understanding of women and motherhood. Furthermore, some women embraced the power and sense of fulfilment found within the roles of wife and mother (Baber & Allen, 1992; Somerville, 2000).

Maushart (2005) referred to the pro-family movement of women as ‘maternal feminism’ stating the need for further public discussion for an understanding of the meaning of motherhood. Motherhood is considered a critical transition in a woman’s life (Oakley, 1980) and despite undergoing constant redefinition, feminists claim the role of motherhood remains devalued and restricting (Burns, 1994; Summers, 2003). Oakley (1980) argued the adjustment to this role is associated not only with disruption to lifestyle but also loss of identity. Within the setting of a neonatal nursery expectations of a mothering role included spending time with the infant (Walker, 1998), which correlated with ‘being there’ and ‘devoted time’, considered more generally as the essence of good mothering (Richards, 1997, p.167). It is within this context of role perception of mothering, located in a particular setting, that this study was conducted.

A postmodern feminist approach was well-suited to this study which seeks to hear the voices of women in order to discover their experiences as mothers from a woman-centred perspective (Humm, 1995). Neonatal literature suggested women are oppressed as individuals in nurseries (Fenwick et al., 2001b; Wilson et al., 2005). To a certain extent, mothers in the nursery are ‘invisible’, by their physical absence, lack of defined role and restricted advocacy for their infant. Paradoxically, they are also extremely visible and in a sense, exposed. The feminist approach taken in this study helped to make ‘the invisible [women] visible’ (Reinharz, 1992, p. 248). The construction of the potential for change for mothers in SCNs demonstrates a key purpose of feminist research, to bring about social change (Humm, 1995) and to create improved institutions (Reinharz, 1992), whether for the institution of motherhood or in neonatal nurseries within hospital settings.

The current research, within this feminist approach, was written to contribute to knowledge and also for the benefit of mothers, as it is intended that issues identified will improve neonatal nursing practise to accommodate women's needs.

Approaching this study as a feminist researcher was more likely to achieve my research goals of hearing women's stories, interviewing not as a researcher but more as a woman and mother, and most importantly, creating an agenda for change as a result of findings. Postmodern feminisms created the opportunity for generating change while acknowledging the tensions and contradictions affecting women within the family and allowing for multiple and contradictory perspectives to be explored (Baber & Allen, 1992). Women's reality as mothers is diverse and a qualitative methodology that facilitates understanding these differences was important. Therefore, an interpretive descriptive approach was selected as appropriate. The next section focuses on the methodology and its relevance to the study.

Interpretive Description

> A good piece of research will make sense of something that clinicians ought to understand (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, p. 8)

Interpretive description has developed as a methodology to provide nursing inquiry with its own, rather than the adaptation of more traditional methodological choices (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997; Thorne et al., 2004). This approach seeks to describe experience through analysis of participants' interpretations; therefore, my

analysis of this study's findings was an interpretation of the experience through which meaning was revealed (Thorne et al., 2004). Sandelowski & Barroso (2003) argue that methods in qualitative research are often described inaccurately, with the findings and particularly the analysis having little relevance to the stated methodology. Furthermore, clinical researchers with their goal of application to practice, may be hesitant to align themselves to 'grand' theories (p.10) but use theories from other disciplines, such as social sciences, yet their ultimate goal was generation of nursing intervention (Thorne, Joachim, Paterson, & Canam, 2002). With the practical focus of nursing and midwifery, and my clinical background, 'informing clinical reasoning' (Thorne et al., 2004, p. 7), as well as developing an empathetic understanding (Rubin & Rubin, 1995), was a valid approach to this investigation. The use of interpretive description enabled me to find patterns within the data and extended my insights into the experiences of participants. As a clinical researcher, I was able to find sense in the results which provided a backdrop for assessment and interventional strategies and will ultimately be applied to practice decisions (Thorne et al., 2004). The main purpose of nursing and midwifery research, in addition to adding to knowledge, should be to improve practice by constructing nursing interventions which are implemented in the clinical field.

New methodologies with less rigidity than more conventional ones, encourage a sense of the 'unknown' (Chadderton, 2004, p. 13) which became apparent as I interacted with and interpreted the participants' interviews. An interpretive approach enabled a reconstruction and understanding of their experiences. Thorne et al. (2004) claim that the rapid evolution of qualitative inquiry, means there are legitimate approaches as yet unidentified or

named. However, these methodologies are used increasingly to generate credible knowledge in contemporary health care contexts. Similarly, topics discussed with women during interviewing may 'have no name' (p. 23), but represent many fundamental aspects of women's lives (Reinharz, 1992). The use of interpretive description as a methodology meant I was able to engage in rigorous inquiry as a qualitative clinical researcher. Methodologies from other disciplines demand the researcher adopt a certain 'outsider' stance (Morse & Richards, 2002, p. 50) and this was incompatible with my clinical experience and associated presuppositions, as well as feminist interviewing principles. The intention of interpretive description is not to develop new theories but add to knowledge with 'tentative truth claims' (p. 7) which are accessible to clinical practice (Thorne et al., 2004). Hence, the interpretive findings may be applied to both practice and knowledge.

Interpretive description is an 'inductive analytic approach designed to create ways of understanding clinical phenomena' (p.1); as such, it has moved beyond established methodologies to become recognized as a credible alternative (Thorne et al., 2004). As a methodology, it was appropriate for this study as it acknowledged the constructed nature of the nursery experience from participants. Through an interpretive approach, meaning emerged through interaction with the data (Rubin & Rubin, 1995), interaction occurred repeatedly, through listening to tapes and reading transcripts. Reflexive interpretation has been defined as the 'open play of reflection across various levels of interpretation' (Alvesson & Sköldberg, 2000, p. 248) and the interpretation was dependant on my judgement and intuition. Ongoing use of a journal allowed further personal reflective

thought throughout this study. An understanding of the 'overall text' (p. 31) of the conversation and finding contextual meaning through inductive analysis was central to an interpretive approach (Rubin & Rubin, 1995); a reconstruction of the participants' perceptions was therefore possible. The next section illustrates the alignment of the feminist perspective and interpretive methodology to my role as researcher.

Role of the researcher

As researcher, my position and assumptions were paramount to this qualitative research, particularly when using a generic approach, such as interpretive description (Caelli, Ray & Mill, 2003). The stance and location is the most significant aspect of using a method (Morse & Richards, 2002) and my aim as researcher of taking the findings back to practice and improving care for women is highly relevant to the choice of methodology, in conjunction with its congruence to postmodern feminist theories. The 'motives, presuppositions, and personal history' (p. 9) of a researcher guide the inquiry, and engagement with the data subsequently shapes the analysis (Caelli et al., 2003); as interpreter I had a responsibility to reveal my position. Furthermore, Oleson (2000) claimed researchers in interpretive qualitative studies bring characteristics and attributes which shape the process of the research interaction.

Despite not experiencing premature birth myself, I have observed and cared for mothers of premature infants for many years, albeit in a non-research role. These observations and my involvement with these women, generated a curiosity - what was it like for them in the nursery? As a mother, I felt great empathy for these women separated from the infants

and having to leave them every night, sometimes for several months. As a midwife, I was conscious of the confined and sometimes oppressive environment of SCN that was shared by many individuals. With my predominantly clinical background, my goals in this project were to hear how women interpreted their roles in the nursery and through this, generate knowledge with clear significance to other midwives, to further develop understanding and therefore improve care. Clinical researchers often need to address their inquiry through a qualitative approach and one main commitment as a midwife was ‘linking theory to practice' (Rapport, 2004, p. xviii), and reconciling the theory-practice gap, hence the choice of a more practical methodology.

Data collection was by interviewing but working within the field, although not with participants, inadvertently generated further experiential knowledge. The nature of the study became apparent through observation within the SCN setting; as an emerging researcher, I began to travel through the nursery with women and record my interpretive insights in journal form. An essential aspect of a reflexive research process was introspection and ‘processing’ of my emotions (p. 217) as part of ongoing self-appraisal (Alvesson & Sköldberg, 2000). Keeping a journal assisted in examining my own thoughts and was crucial to my being reflexive throughout the research process. Reflexivity is ‘coming to know the self within the research process’ (p. 183) and was essential to the study, philosophically and methodologically (Lincoln & Guba, 2000). As researcher, positioning myself behind participants in order to consider the research project, demonstrated ‘strong reflexivity’ (Harding, 1991, p. 163). Likewise, interpreting the events through women’s stories became a valuable way to view familiar events as

unknown while trying to identify different patterns (Alvesson & Sköldberg, 2000). Researchers' predetermined assumptions have been criticised as restricting the depth of enquiry in the interview process (Chadderton, 2004), however, 'emotion is an inevitable and important part of the of the researcher's motivation and choice of orientation' (Alvesson & Sköldberg, 2000, p. 217). Undoubtedly, an emotional curiosity had driven my interest towards this study initially. Personal (mother/woman) and professional (midwife) engagement with participants and ensuing data was emotional at times and it would be naïve to think otherwise, given the nature of the study. In addition, some critics argue it is untenable to set aside presuppositions and 'freeing oneself from preconceptions is ... a pious hope rather than an achievable goal' (Alvesson & Skoldberg, 2000, p. 291). In summary, emotion and intellect were inseparable (Alvesson & Sköldberg, 2000; Hesse-Biber & Leavy, 2004) and integration of these characteristics was essential as I entered the research process.

The qualitative nature and feminist approach of this study necessitated researcher reflexivity combined with insight regarding possible influences from my background: my 'cultural self' (p. 229) was considered a set of resources for the study (Oleson, 2000). While observing, consciously and otherwise, mothers attending to infants in the nursery, I was aware of the *ease* of observation of individuals within an environment which had been designed with that purpose in mind. The observation was a two-way process with mothers watching staff and staff watching mothers, and the exposure of all individuals impacted in many ways. My possible influence on the findings were acknowledged and applied, to complement the interpretive nature of the study (Dionigi, 2003; Morse &

Richards, 2002). Indisputably, immersion in women's stories required both empathy and a certain 'subjective involvement', (Stanley & Wise, 1993, p. 113) and feminist underpinnings of this research required a reflexive approach that included my position in the investigation (Ezzy, 2002). My presuppositions about nursery mothers included their relative silence in SCN in terms of not only their immediate needs, but also their life outside of the nursery. For several years preceding this study, I had always been aware and concerned about the apparent susceptibility of new mothers to the rules, routines and whims of this environment. Encouraging them to speak of their experience and validating what they said provided some participants with the sense of revelation (Reinharz & Chase, 2001), and from a feminist philosophical perspective, the process of interviewing as a means to accessing women's ideas has been considered an 'antidote' (p. 19) to the centuries of women's silence (Reinharz, 1992).

The aim of this research was to provide a rich description (Morse & Richards, 2002), of women's interpretations of their roles within regional SCNs. The perception of their roles, what they felt their identity was and how they perceived the environment, were all facets within the open-ended question, 'what was it like having your baby in the special care nursery?' As a midwife who has spent many hours assisting and observing the ambience of the nursery and the interactions of the actors within, this study blended both professional and personal inquiry. This was well represented using a postmodern feminist approach and a generic qualitative methodology, interpretive description. Furthermore, it was anticipated that this study would generate findings which will contribute to the

understanding of how women with hospitalised premature infants interpret the experience.

Method

In-depth semi-structured interviewing

Eight women agreed to take part in this research, sharing their stories of regional SCNs and subsequently participated in interviews. The aim of this qualitative study was to uncover unanticipated and new areas of knowledge (Britten, 1995), through a high standard of in-depth interviewing. In-depth semi-structured interviewing was the best approach for this study, because minimal structuring of the interview process allowed a richness of conversation which uncovered other aspects within the broad domain of the research question. In-depth interviewing is defined as ‘guided conversation’ (Kvale, 1996, p. 4). However, interviews differ slightly from ordinary conversations due to the required intensity of listening and the need to ‘hear the meaning’ (Rubin & Rubin, 1995, p. 7); rapport with participants was enhanced by ‘strong listening skills’ (Reinharz & Chase, 2001, p. 229). Development of these skills was assisted by years of experience listening to women describe their births and breastfeeding issues through my work as debriefing midwife and lactation consultant. In-depth interviews encouraged participants in a similar situation to provide multiple perspectives of the experience (Johnson, 2001).

Semi-structured interviewing is a common method of qualitative data collection which involves active involvement of participants, and is considered a valuable means of gaining insight into the human condition (Reinharz & Chase, 2001). Interviewing with a

feminist approach allowed participants to answer with their own descriptions and encouraged a rapport through engaged conversation (Reinharz, 1992). Open-ended questions guided the interviews to discover meaning behind women's perceptions of the nursery. A feminist underpinning in interview approach aimed to dispense with traditional hierarchical interviewing (Hesse-Biber & Leavy, 2004), and the nature of the interview revealed data which may have not otherwise been obtainable. The gender standpoint of feminist interviewing has been criticised for lack of egalitarian aspects of race, class and sexual orientation, but the 'woman-to-woman' (p. 229) conversational style of interview tended to capture participants' perceptions (Reinharz & Chase, 2001). In this study, the relationship between participants and myself was intersubjective meaning the interaction incorporated empathy and emotions (Kvale, 1996). Consequently, interviews were friendly dialogue rather than interrogation (Ellis & Berger, 2001). Furthermore, Roberts (1981), affirmed when interviewing women, there is 'no intimacy without reciprocity' (p. 49) and the sharing of personal information in addition to a non-judgemental attitude, helped encourage familiarity during interviews.

By adopting the method of in-depth interviewing, I sought a deep understanding of the participants' situation which extended beyond 'commonsense' explanations to knowledge 'hidden from ordinary view' (Johnson, 2001, p. 106), yet a semi-structured approach defined the area of inquiry (Britten, 1995), in regard to participants' perceptions of their roles. My clinical experience and 'insider' knowledge provided a good foundation from which to conduct interviews, however acknowledgement of pre-conceived assumptions was essential, as they may have influenced the interviewing process (Johnson, 2001). For

example, it was difficult not to assume the situation of being separated from their infant was intolerable for all participants. The acknowledgement of my familiarity with the environment and its practices was made evident by participants' asides such as, *you know what I mean*. Extensive knowledge of the nursery environment facilitated probing questions and further depth of meaning during interviews and analysis.

The emphasis in a research interview is on intellectual understanding (Kvale, 1996), and the essence of the interview is interpretation of the meaning of participants' dialogue (Reinharz & Chase, 2001). Mutual trust was facilitated by reciprocation of views and feelings between participants and myself during interviews (Johnson, 2001). Rigour in the interviewing process included my efforts to adopt a blend of 'observation, empathic sensitivity and intellectual judgement' (Fontana & Frey, 2000, p. 651), characteristics frequently adopted in the clinical setting. The interview process, as anticipated, took a direction of its own at times, and followed the line of each participant's discussion; occasionally the conversation needed guiding 'back on course' (Johnson, 2001, p. 111). However, 'wandering together' (Kvale, 1996, p. 4) conversationally with participants was a metaphor for exploring the nursery in a new light and the 'journeying towards' many truths (Chadderton, 2004, p. 13) took us through a process of discovery. The aim of this in-depth interviewing was to uncover unanticipated and new areas of knowledge (Britten, 1995) and interactive in-depth interviews proved a suitable method for a rich, interpretive study (Morse & Richards, 2002).

Ethical issues

Ethics approval for this research was obtained from the University of Ballarat's Human Research Ethics Committee before the recruitment of any participants. Prior to meeting women for interviews, I advised them of my employment in one of the regional hospitals as a midwife and lactation consultant as I may have cared for them during their infant's stay. Consequently, there was a chance some participants may have known me through my employment within the hospital, but it was reiterated that the interview was not part of the professional relationship. Care was taken to ensure that none of the interviews adopted a therapeutic relationship (Kvale, 1996), yet the exploration and reflection on experiences in SCN provided a form of debriefing for some women and emotional issues arose. Some participants were still angry regarding aspects of care and one interview was ceased when a participant wept as she recalled her daughter's pain during medical procedures.

Participants were able to withdraw from the study at any time. Previous experience in debriefing has developed my sensitivity to the need for further professional assistance if counselling was required for participants. Processes were in place to direct women to professional help and to offer referrals in the event of undue distress. Contact numbers of local counsellors were provided to any participant who became distressed or who had unresolved issues from their premature birth or experience of the neonatal nursery. They were also advised to contact their General Practitioner should the need arise. However, participants declined the offer and stated they felt well-supported by family and friends. In addition, a telephone number for Lifeline was provided. Lifeline provides a network of

telephone counselling centres across Australia. As researcher, I had an obligation to minimise possible harm to the participants.

Issues of confidentiality were emphasised given the regional focus of the study where there was a greater chance of future contact with health professionals or other individuals from the respective hospitals due to social proximity. Assurance was given that no information would be discussed with the hospital. In the transcriptions of interviews, nurseries were not identified by the name of the institution but by a generic, 'special care nursery.' Pseudonyms have been used to protect the identity of participants and some details were withheld if they were likely to identify participants. The tapes, transcriptions and interview notes were stored in a locked cabinet in my office at home. They were labelled with a coded letter, the date and place of interview. A password protected data on the computer. All field notes and recordings of interviews were sealed in boxes and will be kept in a locked cabinet in the office of the principal researcher in the School of Nursing at the University of Ballarat for a period of five years following publication of the data. Only the research team have access to the data.

Women with involvement of welfare services such as Child Protection, or those with specific social issues such as drug addiction, were excluded from the study as they have been identified as a particularly vulnerable population. Socially disadvantaged women have difficulty accessing resources and may be reluctant to disclose their needs for fear of being reported to authorities (Sword, 2005). However, the possible challenges facing

these women in addition to having a premature infant and the paucity of literature warrant further research in the future.

Recruitment of participants

Due to the nature of this in-depth qualitative study, a small number of participants were selected. The eligibility criteria for participants were as follows:

- Over the age of 18 years
- English speaking
- Infant to have been in a regional special care nursery for at least ten days
- Reside within regional Ballarat or Geelong area

Mothers over the age of eighteen years were selected to avoid the issues of consent of minors and English as a first language maximised interpretation of data with a commonality of language between participants and myself. Mothers with infants in the nursery for a minimum of ten days have had the opportunity for sufficient exposure to the nursery environment to comment extensively on their experience. Participants who have been well 'enculturated' in the setting (p. 110), and can thoroughly describe their situation, are likely to make the best informants (Johnson, 2001). The regional areas which were targeted due to geographical location and convenience were Geelong and Ballarat. Both these areas offer level II SCNs in their hospitals.

Participants selected were the first eight volunteers to meet the criteria and consent to interview. Five other volunteers were unsuitable due to geographical location or infants

greater than twelve months of age. The participants were recruited through a number of mediums: Maternal and Child Health Nurse centres, using coloured A4 posters and fliers, advertisements in 'PremiePress' newsletter, and through the Austprem website. Premiepress newsletter is an Australian publication produced quarterly and aimed at a readership of neonatal nursery staff and parents (see Appendix). Austprem is a non-profit organisation with a website designed to provide information to parents of premature infants. Advertisements invited women who had given birth to a premature infant within the last twelve months, to participate in the study and describe their experiences within the SCN.

A contact phone number for the university as well as my email address were provided on the flier. Most potential participants made initial contact through email and each received a plain language statement and consent form, via post or email. During this initial contact, by telephone or email, any questions by women were clarified, and the interviewing process of audiotaping and note-taking explained. Confidentiality was assured, particularly as some infants had been cared for in my workplace, although I was not directly involved in any of their care. It was explained that participants' anonymity would be maintained through the use of a pseudonym if they preferred.

Once participants had agreed to participate, further contact by telephone was made to arrange a mutually convenient meeting time and place. This telephone conversation provided me with the opportunity to introduce myself as a 'sensitive learner' of their experiences (Fontana & Frey, 2000, p. 655), and assisted in the development of trust prior

to meeting them for interview. The size of the sample generated adequate data to identify common themes; 'enough' interviews (p. 113) was the number that provided adequate information to answer the question (Johnson, 2001).

Preparation for fieldwork

Field notes were valuable but tape recording was essential for in-depth interviews. When the interview was recorded verbatim, the likelihood of a valid analysis was greater as data is collected in the participants' own words (Johnson, 2001). Appropriate use of equipment was essential for clear recording of data (Kvale, 1996), therefore it was imperative that the tape recorder and tapes were high quality and I was familiar with their use. A poor quality recording may have lead to misunderstanding or misinterpretation of data. Practise interviews under the supervision of the research team refined the interviewing technique and allowed identification of problems, such as acoustic difficulties, before actual data collection (Kvale, 1996).

My practise interview of a friend who had an extremely premature daughter fifteen years ago, allowed some refinement and clarification of the questions and a chance to 'listen to myself' as interviewer. This also alerted me to the impact of extraneous background noise and the need to check equipment during the course of the interview. Strategies undertaken to minimise problems included: the use of high quality equipment, familiarity and testing of tape-recorder prior to interview, testing recording with each woman prior to interviewing, appropriate placement of the recorder, selecting a quiet area and ensuring

clear pronunciation. It was prudent to take spare equipment, including batteries in the event of any problems.

Data Collection

After women had agreed to participate and signed a written consent, they were interviewed at a place convenient to them. Except for one, all participants elected to be interviewed in their own homes at a time when their infants were most likely to be asleep. The issue of travel was accentuated for me, as I traversed the winding dirt roads, which the women would have travelled on a daily basis for the many weeks their infant was in SCN. Currently, distance to health services is measured in kilometres but due to varying quality of roads and driving conditions, Australian Institute of Health and Welfare (2003) recommends travel time may be more relevant than distance. It was easy to imagine the daily trips, usually travelled alone, accompanied by an 'Esky' of breast milk.

Permission for audiotaping was obtained from the participants prior to the interview and this was confirmed at the meeting place. The interviews were audiotaped with the condition that the tape may be ceased at any time. Data was collected over a total of fourteen hours. All participants had their infant with them at some stage during the interview and sometimes 'included' the infant in the discussion. Ages of the infants ranged from two to twelve months. Often infant care such as nappy changing and feeding were carried out during the interview. An ice-breaking chat tended to precede the interview, with conversation generally pertaining to the infant, but also issues of living in rural areas, such as distance to facilities and isolation. A sense of connection was

developed with women as we shared some common ‘ground’– rural living, SCN anecdotes, and being women and mothers in regional areas. Several participants owned horses as I did and a ‘horsey’ discussion would ensue, helping to build rapport prior to interviewing. As a researcher, gaining participants’ trust by a truthful self-representation helped to ensure honesty in their answers as opposed to giving the answers they think I wanted to hear (Fontana & Frey, 2000). In addition, mutual understanding of each other (Rubin & Rubin, 1995), ensured clarity in conversation and validity of data. During this time, demographic data were collected including age, marital status, parity, birth events and details of the nursery stay of the infant, including transfers to and from tertiary centres in Melbourne.

Interviews were semi-structured but very informal, with a ‘chatty’ approach and usually over a ‘cuppa’, which lessened the barrier between the participant and myself. If the conversation gravitated towards difficulties in parenting a young infant, my personal account as a mother who also found mothering difficult, seemed to put participants at ease. Furthermore, it detracted from my professional role as midwife/lactation consultant, and this less hierarchical and more intimate relationship lent itself to further disclosure, from both participant and myself (Reinharz & Chase, 2001). The key topics referred to perception of the neonatal nursery, participation in care of the infant, and if and when a sense of motherhood arose for women during this time.

The questions loosely guiding the interviews were:

1. Can you describe your experience of having your baby in the special care nursery?
2. What did it mean to you having your baby in the SCN?

3. How would you describe your role or identity within the SCN?

4. What were some of the experiences of being a parent when your baby was in the SCN and what made you feel like a mother?

Most women required few prompts to tell their stories and any aspects were clarified during the course of the interview, by reflecting my interpretation of the story back to participants. Prompts such as, 'is there anything else you would like to add?' or 'what was that like for you?' sometimes precipitated a detailed discourse of nursery experiences that the participant may have reflected on from an earlier part of the interview. Some of the participants' dialogues included criticism of care and suggestions for improvement; the journal also allowed me to note-take for future reference. During the interviews, I made pertinent notes at certain points in the conversation, where body language exemplified the verbal message, or in some instances, contradicted it. Interestingly, some participants disclosed further information following cessation of tape recording. Restraint in directing the interviews and imposing personal beliefs was assisted by the use of a journal throughout the research project, which allowed personal reflection. Following the first interview, my knowledge base was added to and guided interviews with other participants in terms of verification of certain issues (Johnson, 2001), and appropriate prompts without disrupting women's accounts.

Transcription

Interviews with participants were the raw data, but transcription was necessary in order to read the stories, allowing greater familiarity and identification of common patterns or differences. The transcription was an 'interpretive construction' (p. 165), where

participants' oral language was translated into written discourse (Kvale, 1996). Wellard & McKenna (2001) proposed advantages for and against the researcher transcribing the data, rather than employing a transcriber. Initially, due to time constraints, I had intended to employ a transcriber for at least some transcriptions. However, after one transcription, I recognised the value in transcribing myself with the familiarisation and insights I gained with the data, therefore I continued to transcribe all tapes. It also provided me with a confronting observation of interviewing technique and allowed for some refinement, such as more astute listening for cues.

Tapes were transcribed using a software programme, Dragon Voice recognition and each one hour tape took between three or four hours to transcribe. Using this effective software, my own voice profile was created, which then allowed continuous dictation which was transcribed into text. The procedure for transcribing included: verbatim transcription to obtain richness of raw data; documentation of non-verbal responses and emotions; and repeated listening and correlating tapes to transcription (Kvale, 1996). Although time consuming, transcription allowed detailed reflection of the participants' responses, verbal and non-verbal, and thus served as another part of data analysis (Ezzy, 2002). The interviews were repeatedly listened to and the transcriptions read, which allowed thorough immersion and familiarity in the dialogue. Often, I would replay the tape on the journey home from a participant's house, a trip which sometimes took up to two hours. The nuances through tone and pitch, and emotional tension in the voice were impossible to transpose to the written word, hence the advantage of thorough immersion in the taped data. The 'pallor' of the written word (Kvale, 1996, p. 26), in comparison to

the emotion conveyed through women's voices was well illustrated when reading through transcriptions, but my familiarity with the tapes meant I could 'hear' the text during analysis.

This immersion in the data during transcription facilitated the process of 'getting inside' the data (p. 114) and identifying meaning (Morse & Richards, 2002). Hearing participants' voices facilitated my understanding of their perspective within the nursery. Verification was obtained by reading the transcripts while listening to the tapes; this also facilitated a broader interpretation of the dialogue. Undertaking the transcriptions myself, reflected the interpretive methodology utilised in this study as different insights are obtained through listening (Thorne et al., 2004). Listening to the tapes several times helped me to revisit the interview itself. Farm sounds as background noise, or alternatively silence, epitomised the rurality of location and also the geographical isolation of some women. During interviews and transcription, I made notes of relevant visual and emotional aspects, such as body language, voice tone and personal interaction, to enrich the text and more fully represent the data. Preliminary themes and interpretations were documented in a journal for early reflection, and this was valuable in setting aside presumptions, both personal and from the literature. Furthermore, repeated immersion in the data accompanied by synthesis and recontextualisation (Thorne et al., 1997), ensured an intimate knowledge of individual cases for analysis and allowed encapsulation of common themes.

Validity

Validity of the research was ensured by the use of an appropriate methodology to the research question and my ongoing responsibility for coherent findings and conclusions (Chadderton, 2004). Accurate representation of the data ensured validity of this research with an emphasis on 'methodological cohesiveness' (Morse & Richards, 2002, p. 171). Interpretive description with a feminist underpinning, using in-depth interviews demonstrated such cohesion. Skill with interviewing, interpretation and discussion were paramount to quality of the study (Morse & Richards, 2002). Rigor in qualitative research includes an appreciation of subjectivity and complexity, and this was facilitated by my 'getting close' to the participants' world and experience (p. 54), and taking their journey through the SCN, hence the suitability of in-depth interviewing (Ezzy, 2002).

Validity also included a presupposition that women were truthful in their responses and that I would truly 'hear' what was being said with 'sensitive receptiveness' (Kvale, 1996, p. 33). Responsive, active listening with strategic probes but minimal interruption validated the interview (Morse & Richards, 2002). A lengthy practise interview was valuable for this reason. Probes to clarify issues or elicit more information during the interviews, were used with two more reticent participants.

The research interview as 'conversation' (p. 65) occurred when participants and I negotiated on their meaning and the ideal interview was interpreted at completion of the interaction (Kvale, 1996). Interpretations of the participants' dialogues were reflected back to them during the interview to validate meanings and minimise misunderstanding

of data (Britten, 1995). The meaning of both the spoken and unspoken was verified by returning the meaning back to participants throughout the interview as a means of confirming my interpretation (Kvale, 1996). Open-ended questions and minimal 'leading' questions (p. 33), with the absence of presumed themes for analysis also maintained validity (Kvale, 1996). Any direction on my part during the interview was minimised by appraising the tape recording of both the practise and the first interview before proceeding with the others (Britten, 1995). Tapes were transcribed as soon as possible following each interview and field notes read through. Through the analysis process I listened to the tapes while reading transcribed data to check accuracy and minimise errors. This ensured reliability of transcriptions (Wellard & McKenna, 2001) and hence contributed to validity of the study.

Interpretive description was highly suitable for discovering the perceptions of mothers in SCNs and representing findings to relevant clinicians in a descriptive form (Thorne et al., 2004). Three characteristics of interpretive description ensure credibility: the research process, the intersubjective construction of knowledge and the researcher's stance (Thorne et al., 2004). Tension between possible presumptions on my part and insider knowledge was overcome by striving for 'deliberate conscious naivetee' (Kvale, 1996, p. 35). Validation of findings was provided by presenting summarised versions of transcriptions with identified themes to participants, as a generic piece for reflection after the interviews, to ensure their meanings are clear. A thematic summary reduced the length and possible incoherence of verbatim transcription. In addition, the thematic interpretation was presented to colleagues in my workplace to confirm tentative truths

and new understandings. This reflexive reconciliation of knowledge, interpretation and practice was paramount to me as a neophyte researcher with one foot firmly within the clinical setting. Therefore, it was essential the interpretive description passed the 'thoughtful clinician test' (Thorne et al., 2004, p. 17).

Analysis

Data analysis began and continued during data collection; this integration was considered an essential feature of an inductive and interpretive qualitative method such as interpretive description (Ezzy, 2002). The aim of the analysis was to develop a coherent understanding and explanation of the data (Kvale, 1996), however, congruence to a postmodern feminist approach meant that the analysis was not absolute due to constant changing of reality (Jones, 2004). Similarly, the product of interpretive description asserts a 'tentative truth claim' (Thorne et al., 2004, p. 7) rather than absolute 'facts'. Interview analysis began during the interview as women described their interpretation of a SCN and their roles within. Following transcription, the main part of analysis took place: clarifying meaning by identification of the 'essential and the non-essential' (Kvale, 1996, p. 190), which was directed by the research question of the women's perception and interpretation of their roles within the nursery.

Due to the small size of this study, computer programmes such as Nvivo were not utilised. As the researcher, I was the investigator behind the interpretation and my 'researcher's consciousness' (p. 15) was influential in the construction of the findings (Thorne et al., 2004). A thematic analysis was applied to separate the transcribed

interviews into parts by categorising and grouping according to commonalities and differences. Qualitative inquiry which involves ‘theme-ing’ of data (p. 145) allowed a variety of ways of approaching and working with the data, (Morse & Richards, 2002). Themes have been defined as ‘meanings implied from words and behaviour’ (DeSantis & Ulgarriza, 2000, p. 363) although the lack of clear definition may confound analytical rigor. As themes became apparent in this data, through a process of emergence and extraction, (DeSantis & Ulgarriza, 2000), they were sorted into sub-themes. The sub-themes were not strictly determined and evolved through an inductive approach (Ezzy, 2002). Commonalities and differences were identified through repeated reading of transcripts and immersion in the data. Understandings identified in the literature review as well as my clinical background formed a foundation for induction of themes from the data (Ryan & Bernard, 2000). However, navigating ‘within and beyond’ the theoretical framework (p.9), required a certain distancing to allow for less obvious categories to be determined (Thorne et al., 2004). Challenging some preliminary interpretations of data (Thorne et al., 2004), was part of the inductive process of analysis; similarly, moving beyond the analytic categories within the literature review, was necessary to accommodate irregularities. For example, spatial aspects emerged as a dominant theme in the findings and this extended well beyond references to the nursery environment in published literature.

In keeping with the philosophy of interpretive description, precise and meticulous coding of data was avoided; the process of broadening the conceptual links during analysis reflected the objective of ‘breadth is more useful than precision’ (Thorne et al., 2004, pp

10-11). The key steps of the analytic process were: ‘comprehending data, synthesizing meanings, theorizing relationships and recontextualizing data into findings’ (p. 11); therefore, loosely related ideas were developed into coherent patterns (Thorne et al., 2004). Categorising as the first step began to transform the data into themes (Morse & Richards, 2002), but excessive coding was avoided so patterns within the broader context were found (Thorne et al., 2004). Validity was ensured by showing the meaning beyond the themes identified within the study (Caelli et al., 2003); these meanings were verified by the participants to ensure accuracy of findings. Explanation of findings was through interpretation and description (Chadderton, 2004) and meanings were developed using an interpretive descriptive approach (Thorne et al., 1997).

Therefore, description of the interviews was analysed within the theoretical framework of the study (Morse & Richards, 2002), whilst allowing for some deviation if indicated (Thorne et al., 2004). The feminist framework supported a ‘heightened moral concern’ for women (p. 659) and an acknowledgement of the paternalistic power structure (Fontana & Frey, 2000). Insights and understanding gained from listening to tapes differed from those induced by reading transcripts; employing both methods assisted in understanding the meanings within the data. As researcher, I was ‘interpreter’ (p. 12) and therefore an essential player in determining the relevance of data in relation to the research question (Thorne et al., 2004).

Conclusion

The framework and methodology chosen for this study were selected because of their suitability for the research. An interpretive qualitative methodology applicable to 'practise-disciplines' such as nursing or midwifery, utilised in-depth semi-structured interviewing to uncover meanings of women's roles within regional SCNs. The underpinning postmodern feminist framework was reflected in the nature of the interviews and interpretation of findings. The acknowledgement and respect for diversity was indicated in the choice of a postmodern feminist perspective and a less traditional, but independent qualitative methodology. Thus, the central role of women in the study, the clinical perspectives of both the setting and my stance as a midwife, justify the methodology selected. The qualitative and small nature of this study excludes the intent to generalise findings, however, the individual's experience contains intersubjective meanings that may be shared in a 'subpopulation' (p. 76) or a broader society (White & Klein, 2002). Thus, this interpretive description offers a 'snapshot' of what the experience of having a regional hospitalised premature infant may be like for other mothers.

Chapter 4: Rural women: juggling the load

This chapter presents an introduction to the participants, followed by an exploration of the major findings from the research. Their stories contained descriptions of aspects specific to rural life, such as livestock responsibilities, dirt roads and distance to services. The commonalities and differences of the participants' experiences captured the interpretation and meaning of having a hospitalised premature infant in a regional SCN, and hence offer insights to their experience. As some women referred to their infants as 'baby' and others as 'child', the term infant will be used throughout the thesis to avoid confusion.

Participants

> Rural women…value space and freedom from living in the country (Kenkel, 2003, p. 153)

Figure 2 Rural western Victoria

Eight women agreed to participate in this study. All but one of these women elected to be interviewed in their own home. The other venue was an antenatal classroom in the hospital. This was entirely the women's choice and primarily for convenience, in view of their infants with erratic sleep patterns and demands of young children. Most of the participants resided on acreages in peaceful rural settings, at least fifteen minutes from a regional hospital. The privacy and surrounding space was the antithesis to the confined and relatively busy area of a neonatal nursery. Three participants had access to their homes via dirt roads and one woman included a 'mudmap' to her home in her email.

The ages of participants ranged from 26 to 40 years and all were married. Two of the pregnancies were conceived by IVF and two were unplanned. There was one multiple birth, hence nine infants and eight mothers. Their modes of delivery varied from normal vaginal to emergency caesarean for antepartum haemorrhage. Six of the participants were first-time mothers and two were multiparous, but only one had experienced premature births with her other children. Three of the participants were on maternity leave from their employer; the others worked from home, either in their family business or were self-employed. The gestation of the infants ranged from 27 to 35 weeks. Six of the nine infants spent some time in a tertiary NICU in Melbourne prior to transfer to a regional nursery. For confidentiality, these hospitals have not been specifically identified in individual cases but comprise the Royal Women's Hospital, Mercy Hospital for Women and Monash Medical Centre. The length of stay for infants in the regional centres ranged from ten days to eight weeks. The SCNs were in either Geelong or Ballarat, but further details were not disclosed in transcriptions to maintain privacy. Women are identified in

the thesis with a pseudonym for confidentiality. A brief description of the participants follows as a way of introducing them:

Louise was a 40 year old married woman who helped her husband manage a family business. Her pregnancy was IVF assisted and she gave birth to twins at 27 weeks gestation, following a sudden antepartum haemorrhage. The mode of birth was an emergency lower uterine segment caesarean section (LUSCS) and the twins were transferred to a tertiary centre in Melbourne for intensive care by the Neonatal Emergency Transport System (NETS) immediately after birth. Louise intended to breastfeed and commenced expression of breast milk within 24 hours of their birth and continued expressing for many weeks until both infants were able to breastfeed. One twin was considerably smaller than the other and remained in hospital for three weeks after her brother's discharge home; this particular twin spent five weeks in the regional nursery and a total of 107 days in hospital. At times during the interview, Louise would refer to situations where both twins were still in hospital, or just her daughter, the smaller twin. The twins were three months old at the time of interview.

Betty was a 33 year old, married, self-employed woman who developed severe pre-eclampsia, in her first pregnancy, at 27 weeks gestation and was transferred to Melbourne. Her daughter was born one week later, via an emergency LUSCS. Following a five week stay in Melbourne, during which Betty stayed in a parents' flat near the hospital, her infant was transferred back to the regional hospital for a further five weeks.

Betty provided breast milk for her daughter until she was able to breastfeed. Her eight month old daughter at the time of interview had been recently weaned.

Marion was a 35 year old married woman with three other children, all born normally with no complications. She had a rapid onset of severe pre-eclampsia at 31 weeks gestation and was transferred to a tertiary centre for an imminent LUSCS, the same day. Her daughter remained in Melbourne for only six days, before a transfer to the regional nursery. Marion remained an in-patient in intensive care and then the postnatal ward during the time her daughter was in Melbourne, then suddenly found herself expected to be involved in the care of her infant in the regional hospital despite being unwell and 'severely weak'. Her daughter remained in the SCN, 45 minutes from home, for five weeks. For several months after birth, Marion described waking up thinking she was still pregnant and described a sense of 'feeling incomplete'. She was still breastfeeding her twelve month old daughter and suffers ongoing medical problems including chronic fatigue syndrome with associated depression.

Karla is a 26 year old woman, married to a farmer and living 20 minutes from the nearest regional centre. She went into premature labour in her first pregnancy at 32 weeks gestation, associated with a small haemorrhage. Karla was expecting to have a LUSCS the following day, but laboured quickly and gave birth to a boy in the regional hospital. Her son was breastfed and progressed well. She was originally told her son would be in hospital for six to eight weeks, but he was discharged just under four weeks following birth. She described herself as 'pretty determined' to take him home early. She was

breastfeeding her three month old son and enjoying ‘being a mum’at the time of interview.

Nancy was a 30 year old married health professional who had an IVF assisted pregnancy. She developed pre-eclampsia at 25 weeks gestation and was transferred to Melbourne two weeks later for an emergency LUSCS. Her son developed serious complications and Nancy ‘didn’t think he’d survive’. However, he was transferred to a regional nursery, five weeks after birth. Nancy found the nursery environment relatively familiar, due to her professional background; this also increased her feeling ‘like part of the staff’. She expressed milk until her son was able to breastfeed. The first few weeks after birth, Nancy and her husband would ‘look at each other and cry’. Her thriving eight month old son was breastfed.

Amanda was a 30 year old married professional who was intending to work until seven weeks before the due date. However, she underwent an emergency LUSCS in Melbourne at 31 weeks gestation, for severe pre-eclampsia. She found the recovery after her birth difficult for some weeks, due to pain and transport issues. Her daughter progressed well and was transferred back to the regional centre after one week, where she remained for another five weeks. Amanda was breastfeeding her five month old daughter, but considered her a fussy feeder. She described herself as still traumatised by the experience and found it difficult to look at photographs of her daughter in the nursery.

Jane was a 31 year old married professional who unexpectedly went into labour with her first pregnancy, complicated by gestational diabetes. She gave birth normally at 35 weeks gestation to a boy, now nine months old, who spent seventeen days in the regional SCN. Jane was the only participant living in the regional town; the others all resided at least fifteen minutes out of town. For various reasons, including close proximity, she preferred to 'duck in and out' rather than spend the whole day in the nursery. Due to ongoing breastfeeding problems, Jane weaned her son at four weeks.

Susan was a 32 year old with four other children, all of whom were also born prematurely. She was married and managed a small farming property, 30 kilometres from town. Her husband worked in paid employment in town. All births were by LUSCS, and Susan developed severe hypertension in the last two pregnancies. Her daughter, now three months old, was born five weeks premature but was also small for gestational age. Susan described this recent experience as the worst, due to a general anaesthetic for the birth, separation from her other children and difficulties she encountered with staff. She was determined to remain with her daughter and obtained accommodation within the hospital. Susan also suffered a wound infection after birth and post-natal depression.

These eight women while sharing the commonality of a premature birth had individual and unique experiences. Field notes taken during interviews, depicting visual and emotional features, such as body language and personal interaction, as well as the home setting enriched the audiotaped data. Re-reading transcripts and interview notes, in conjunction with listening to interviews, allowed a deep immersion in the data as a whole,

as well as intensive reflection. Hearing the participant's voice assisted in finding the meaning within the narrative; thematic analysis emerged inductively through this process. Each participant's details are provided in Table 1.

Name	Age	Parity	Gestation	NICU (days)	SCN (days)
Louise	40	2 (twins)	27	70	37
Betty	33	1	27	35	35
Marion	35	4	31	7	42
Karla	26	1	32	N/A	27
Nancy	30	1	27	35	42
Amanda	30	1	31	7	35
Jane	31	1	35	N/A	17
Susan	32	5	35	N/A	21

Table 1

Predominant themes

The four themes interpreted from the text related to: emotional responses to dislocated lives; space; interactions with staff; and women's sense of identity within the SCN. These themes were then explored intensively. The initial analytic phase included identification and exploration of commonalities and differences among the participants' experiences. Common themes were identified through the participant's responses, directly through the text and what was implied in the subtext. Although clearly identifiable, the themes overlapped and entwined closely with each other, forming a pattern dominated by the struggle for control and search for location and identity within the alien environment of a SCN. The reaction to premature birth and arrival of a small preterm infant varied between participants, depending on experience, however all women found the separation from

their infants traumatic. Responses to a premature birth were not necessarily related to gestation or the infant's condition, although transfers to Melbourne exacerbated the fear and anxiety of participants, as the need for neonatal intensive care reflected the instability of their infant. Beyond the immediate crisis of a premature birth, emotional reactions were more reflective of the dislocation of participants' lives and the need to adapt to a new situation within an unfamiliar environment. Within the context of the SCN setting, women's perception of their *roles* was intertwined with the other three themes: *dislocated lives* and *staff interactions* were directly related to the *hospital environment*. As depicted in the following sections, the participants' voices are strongly embedded in the text.

The nursery environment and its effect was a prominent theme throughout women's dialogues. The environment, physical, social and cultural, in which the participants found themselves in the early weeks after birth required major adjustment: attempting to adapt to the setting, familiarising themselves with staff and juggling other commitments in their lives. The adjustment to life in the nursery with a hospitalised premature infant was summed up by Louise, y*ou needed to sort out what you could do.* This encompassed not only what women were allowed to do, but also what they were able to do, both physically and mentally, whether that was handling the infant 'appropriately', providing enough breast milk, caring for other family members, or modifying their behaviour to minimise tension with staff. All participants desired privacy and facilities to remain with their infants.

Most participants considered their adjustment difficult and at times inadequate. Jane felt *quite bizarre because those seventeen days, my life was here in the hospital and nothing outside.* Physiological adjustments following birth, such as maintaining lactation with the expectation to breastfeed and provide breastmilk, were major issues for women, some of whom were recovering from operative births, complicated by medical problems such as pre-eclampsia or infection. Women described feeling unsupported at times perceiving little acknowledgement of their physical needs and discomfort by nursery staff. They struggled to parent; *you want to do what is right, but you can't take on that solo role* [Amanda], and meet expectations of 'good' parenting whether that was their own, staff, family or societal expectations. Women described a major disruption to their lives, exacerbated considerably if they had other children. 'Juggling' their different roles and other parts of their life, as well as navigating their way from nursery mother to what was perceived by participants as normality, required huge emotional and physical input by these women. For Louise, it was sorting out *what was available, what you could ask for, what you could do.*

Dislocated lives: 'Juggling the load'

All participants described similar responses in varying degrees, to the unexpected birth of their premature infant: shock, concern for the infant's well-being, guilt and a strong desire to remain with their infants. The emotional burden was matched by the physiological and practical load of trying to adapt to a new role in difficult circumstances.

For most, the experience of having a hospitalised premature infant was challenging and traumatic.

Shocking really, not good, very stressful. Heartbreaking… It meant having a disruptive life, big time … you feel very lost - awkward, disjointed [Louise]

Emotional distress

For most participants, the transition from pregnancy to the sudden arrival of a tiny infant occurred rapidly, for some within hours on the same day. Rapid transfer to a tertiary centre in Melbourne or the necessity of a general anaesthetic to hasten an operative birth, were examples of events which participants viewed as traumatic. Following birth, the medical focus on maternal complications immediately shifted to the premature infant.

Conditions necessitating urgent birth in Melbourne with gestations of less than thirty two weeks, often meant women had minimal initial contact with their infant, or in one case no contact at all for two days following birth. Louise described incurring the *doctor's disgust* by going to Melbourne by private car against medical advice, desperate to see her twins the day after her emergency LUSCS. Once infants were transferred to regional centres, women remained anxious, but for most their emotional response became more focussed on the day to day routine, visitation and the varying degrees of difficulty in sustaining this. For Karla, [after] *a couple of weeks, it got to a stage where I just had to leave* [the nursery], *it was all too much I think.*

Concern for the infant was overriding from birth, although two participants with larger infants felt reassured by the size of theirs compared to other infants in the nursery and expressed less concern in their dialogue. Jane felt reassured by the staff about her son's condition and was aware of how well he appeared in comparison to other infants in the nursery. *J* [her son] *never really seemed sick, he was just having trouble feeding* [Jane]. However, another participant, Nancy, whose much smaller son developed serious complications, took hundreds of photographs and described being *obsessed by photos because I thought he was going to die.*

Disappointment at an 'incomplete' pregnancy and missing out on their anticipated antenatal course and birth was entwined with feelings of guilt and failure, *you know, you look forward to going to antenatal classes with your husband and we didn't experience that* [and then] *the trauma that we thought we were actually going to lose him* [Nancy]. Susan summed up the entire experience as *an emotional rollercoaster.* Ongoing concern for the well-being of a fragile infant continued well past the discharge for most participants with vivid memories of events within the nursery. Two participants could still 'hear' monitors when they were at home.

Transfer back to regional hospitals represented the infants' physiological stability as well as a step closer to home and participants' expectation of more involvement in parenting. However, several infants developed serious complications in the regional setting and participants remained concerned about their infant's condition most of the time. Marion's reaction to the unexpected transfer of her daughter from an isolette to an open cot

exemplified this constant fear and the staff's response indicated little insight into her overriding anxiety. Marion described walking into the nursery one afternoon to find the isolette her daughter usually occupied was empty, *I turned to the nurses and said, 'has she died' and they started to laugh and said 'no, she's in an open cot'*. Comments such as this not only demonstrate the overwhelming concern women had for their infants but also their desperate need for stability within an unfamiliar space.

Bonding from a distance

Nearly all participants felt compelled to spend as much time near their infant as they could, but ultimately they *had to go every night and leave them in hospital* [Betty, Karla]. Some specifically mentioned 'bonding' and the integral part played by physical contact and closeness, the need to handle and touch their infants: *the contact was exciting - I would write it in my journal* [Louise]; *I did really crave the contact* [Amanda]. Three participants referred to *missing* the first bonding as a result of operative births and the infants being taken to the nursery or in one case, transferred to Melbourne. This was perceived to be something irretrievably lost:

You never got to see her straight away, like hello, and seeing this little blue thing [Susan]

…because I missed the birth altogether, I found that sort of disjointed, like they weren't really mine [Louise]

For Nancy, breastfeeding was a form of physical replacement for *the pregnancy* [IVF] *that I had looked forward to for so long. It was almost that physical continuation with the breastfeeding.*

Physical contact and a sense of 'knowing' their baby seemed to provide a meaning of bonding for some women, but 'feeling like a mum' was not necessarily synonymous with bonding, as bonding implied different meanings to individual women. When questioned about 'feeling like a mum', the response from half the participants related to bonding, these participants implied one was tantamount to the other. However, for other participants, bonding and a feeling of ownership, that the infant was their own, were separate issues. *When I started trying to feed her, I started to think, my gosh, she is mine* [Amanda]. Betty started to feel like a mum when she took her daughter home, but referred to *the bonding side of it* as a different entity, which in her case took over six months. The unexpectedness of a premature birth by an unplanned LUSCS and ongoing separation from her daughter appeared to be major contributing factors for Betty. Marion cried when her daughter breastfed for the first time because to her, it represented normality, *I was just beside myself. I was in tears*. [It felt] *normal - like this is a normal thing to do*. To have a semblance of normality was an anchor for women during this time of dislocation which they described as 'surreal' and 'bizarre'. Three participants mentioned 'bonding' as an essential part of parenting: …*of course you want to be with your baby because you've got to* ***bond*** [mother's emphasis] *with your baby, so you have no choice, you've got to stay there with that baby* [Susan]

…*now I realise that* [the initial contact] *was the bonding* [Jane]

Two participants expressed the fear their infant wouldn't know them if they didn't have frequent contact. Feelings of the infant belonging to them were subdued by a sense of the staff being 'in control', with permission required for many tasks. Most participants

described truly feeling the infant was their own when they left the hospital, although Karla felt closely connected to her son as soon as she felt movements during the pregnancy; these feelings continued immediately after birth, *I really did feel like he was mine.* Some women struggled trying to balance their desire to hold their infant and not over handle them; over stimulation was indicated by staff advice or in one case, the infant's response. Close contact and handling the baby was described as a physical and emotional need*…it was just finding that balance between over stimulating her but having that touch. I would have loved to have cuddled her all the time* [Amanda].

The desire to spend as much time as possible near their infants and hold them was depicted powerfully in the narrative, sometimes as an inexplicable need. However, meanings behind this were complex and not easily discernable. Karla *just had to be there* [in the nursery] where she spent nearly 14 hours a day and Susan *needed that time with her* [infant], *if I hadn't, I would have been at a distance with her*, and later Susan describes her inability to leave her infant behind - *I wouldn't have been able to leave, I wouldn't have left*, despite being desperate to be home with the rest of her family. The issue of 'distance' related to bonding was possibly exacerbated by geographical distance between home and the hospital. Louise and her husband had to *drag ourselves away* from her twin daughter every evening. On the other hand, Jane, appeared less traumatised by the separation and described having her son in the nursery as *a bit of a luxury* [not rooming in].

Participants with other children and limited family support were acutely aware of perceived judgements by nursery staff regarding their limited time within the nursery and that this was a reflection of their 'bonding'. Several participants described examples of nursery staff's expectations of mothers, their attendance and 'performance' in the nursery. *There was the expectation it* [breastfeeding] *would be done every day* [Marion] Betty would spend every day in the nursery for extended periods and claimed *she* [infant] *was in hospital for so long it was harder to bond with her.* It is difficult to discern if the attendance in the nursery was her desire to generate some bonding 'emotions', meet others' expectations of parenting or if in fact she *was* bonding but her own expectations exceeded the experience. The complexities of bonding as a multi-faceted, yet individual process were well represented by this group of women.

Nearly all participants lived some distance from the closest regional hospital. All but one participant lived at least fifteen minutes away and in some cases travelling one way took forty five minutes. Trips to hospital became another task to juggle as some participants organised 'milk runs' (delivery of breast milk), usually by their partner, early in the morning or late at night and others arranged visits around their other children's activities, or transportation by relatives if still unable to drive following a LUSCS. Some participants regularly stayed for the whole day while others made shorter but very frequent visits, such as Jane who would visit up to six times a day.

Separation from the infant was felt acutely with the initial homecoming of women, between three to six days following birth. Leaving the infant behind, for this first night,

heightened the trauma of separation for participants. For some this occurred in Melbourne, although accommodation was found nearby in parenting flats. All participants described intense pain when they left their infant behind as they went home, recalling the exact day of the week.

I'd been fine, didn't feel teary, but that Thursday night when I was going home on the Friday, that was the worst. You almost felt like you were abandoning him [Jane].

That was a horrible day…just awful, I just put a photo by my bed [Karla]. One participant *couldn't leave* her daughter and through negotiations with hospital staff, obtained a parent's room within the hospital, where she remained until discharge. For some participants, leaving their infant every day became easier but for most it remained difficult, even more so with the passage of time.

I would cry most of the way home…it felt like I was abandoning her…like something was missing [Amanda]

Guilt

Participants' sense of abandoning their infants was associated with a fear of impaired bonding and overlayed with intense feelings of guilt. Guilt was a common response with a reported perception of female bodies that had failed to function properly and carry an infant to term, failing not only themselves but also their infant. This was reflected in the language used, particularly by those women who had undergone IVF treatment, whose bodies were not only incapable of *producing* a pregnancy but also *maintaining* one; *the oven broke…I felt pretty ripped off in my pregnancy* [Nancy].

Guilt was not only related to the 'incomplete' pregnancy but also watching their infants endure painful procedures as a result of prematurity. One interview was ceased as a result of a participant's distress recalling her daughter's blood tests and Amanda believed her daughter *associated touch with something that was going to happen to her.* Five participants, all with infants of less than 34 weeks gestation, showed me their infants' residual scars as result of procedures. The ordeal of watching their infants undergo numerous tests was an inevitable part of spending prolonged periods in the nursery.

The use of the term *abandon* used by four participants and implied by others suggested these women felt they had failed themselves and their infants. One participant had been planning a homebirth before developing severe pre-eclampsia. Abandonment assumed a double meaning with women 'abandoning' the infant both antenatally, through a premature birth and afterward, through separation. Karla would not leave her son at night until he was sleep, *so he couldn't see me leaving. I think I felt guilty and I didn't like him to think, oh I don't know*.

The sense of desertion was intensified for the two participants with other children, who were conscious of neglecting their 'other family'. Louise also felt torn between her twins, with one remaining in hospital longer than the other, *I felt guilty I wasn't spending enough time with her and then I felt guilty because he never got a day at home…that was really hard, carting him backwards and forwards*. Concern for older children and in one

case, the partner, was intense and consuming, yet for Susan, the need to remain with her infant daughter overrode all other needs:

I just wanted to get home to me family - it was eating me alive… But I couldn't leave N [infant]. *And it was like I was torn in two* [Susan].

Similarly, Marion described her emotional and physical difficulty managing 'two families':

It wasn't just the baby- my children arrived home at five to four…non-negotiable. I told them [nursing staff] *I could only come in once a day…to them that meant I wasn't bonding…I was struggling with all that while trying to keep the kids feeling normal* [Marion]. 'Juggling the load' both emotionally and physically was epitomised by these two participants with other children. Childcare was required and assistance from family or friends sought and not always given. Two weeks after her LUSCS, Marion was driving herself into hospital twice daily and 45 minutes each way. She vehemently believed there was little support for parents of premature infants.

The intensity of emotional responses by these women demonstrated how difficult they found the experience. Distress related to separation from the infant and fear of not bonding, competed with anxiety about the infant's well-being and the dislocation to their lives. Navigating their way through the environment and attempting to locate themselves within an alien environment, proved challenging in different ways for each participant and is discussed under the next theme.

Space: 'Where am I?'

I felt a bit lost, like I didn't belong…like I was just visiting…they weren't really my babies [Louise].

The notion of space within the SCN was strongly interwoven through the participants' accounts. Apart from spatial aspects, women were unsure of their location in the context of a parental role and other parts of their life beyond the nursery. Thus, the themes of space and roles were closely interrelated. Space encompassed many issues: the physical confines of the nursery, lack of privacy and discomfort with the sense of exposure, the restrictions of the hospital environment, and the difficulty in trying to convert the space into a 'homely' area. In addition, the social space shared with others and lack of personal space of their own resulted in most participants needing to 'get out'. Having an area of their own was closely linked to a feeling the infant belonged to them; participants would take their infant out of the nursery to the lounge *to feel normal* [Amanda].

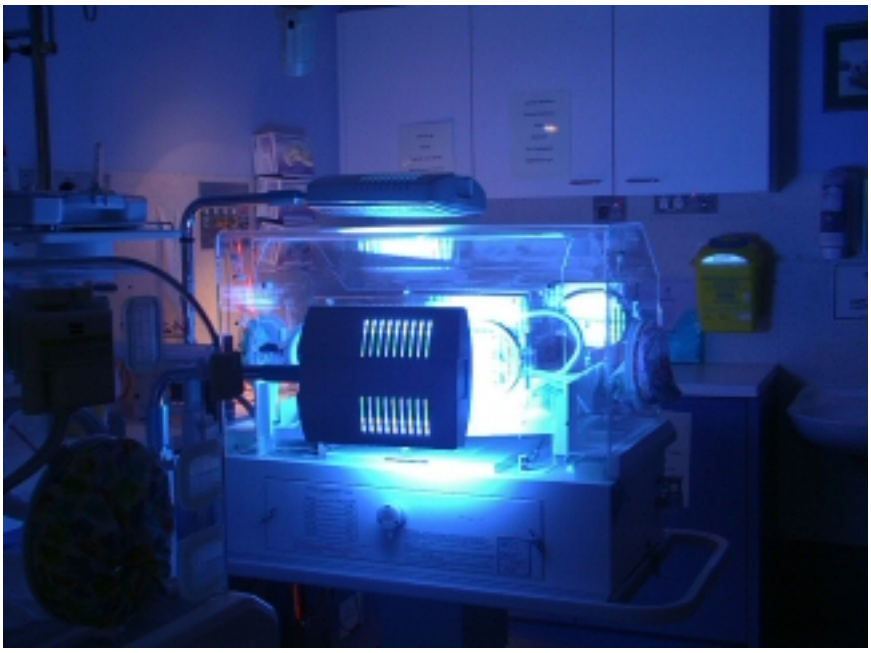

Figure 2. Phototherapy lights over isolette in SCN. *I didn't realise it was a special care nursery* [initially], *I just thought it was a nursery* [Participant]

The Special Care Nursery

The two regional hospitals were of similar size, although one classified as a high-risk Level II, was able to accommodate sicker infants, such as those requiring CPAP. The number of available beds in both nurseries was twelve and eighteen, although participants' descriptions suggested the number of infants may have exceeded this at times. From clinical experience, I am aware of the limited space around isolettes, approximately one and a half metres between each one. The women commented on this; Marion described, the cots were placed as *cheek to jowl*; Nancy stated *you just had to get used to squeezing in and out* and Jane described the open cots as being *not too far away* [from each other], gesturing less than a metre. During interviews, participants would indicate with their hands the distances between cots, or in Louise's case, the distance across which she and her husband conversed when she was 'encouraged' to express behind a curtain.

Both nurseries had *a wall of isolettes* [Nancy] and an open area with a number of open cots *floating out in the middle of nowhere* [Louise], *they'd be lined up over there…or in the middle in a circle…it was just different each time* [Jane]. Most participants described both nurseries as *busy…at times it could get a bit crowded* [Amanda], *there's doctors coming in or bits and pieces going on* [Amanda] or as Susan described *it was packed...like Bourke St,* [in Melbourne], *there were up to 14 babies in there.* Jane also referred to the number of infants in the nursery during her stay and the close proximity, making it difficult to avoid *having a look* [at other infants]. Karla expressed the need to *not to be in the road* [way of staff] when a sick infant was admitted or the nursery

appeared extra busy. She was aware of the nursery being *closed* [not able to admit any more infants] at one stage, because all cots were occupied. Participants with smaller infants who required more care were conscious of alarming monitors, *they were very off-putting* [Marion], whether they were their own infants or not. Both Marion and Amanda stated they still 'hear' monitors months after the birth. These findings indicate participants found the environment crowded, noisy and disturbing.

The nursery staff and their evident control of the environment were an integral part of the women's perception of the nursery space and generally, institutionalised routines dominated the days. Several participants referred to staff not 'liking' mothers performing certain tasks that were seen as staff's responsibility, for example taking their infant out of the isolette to cuddle or feeding their infant via the nasogastric tube. Louise preferred to express breast milk beside her twins' cot yet was made to feel as though *it was not a good thing to do*; she felt the staff were uncomfortable with her expressing without a screen. Marion's comments suggested a controlled environment with strict routines: *the way the special care nursery is, they can't afford people to just waft in and feed at their leisure…it screws up the next feed* [Marion]. The participants' feeling of powerlessness within the nursery area was profound and they referred to *asking permission* for many tasks. According to Marion, *you're very much stepping on their* [nursing staff on night duty] *territory*, but generally she found the day staff *very welcoming.* All participants found some aspects of the nursery disturbing. In-depth conversation with some participants revealed contradictions within what they said and what they implied. Amanda initially stated the environment *was fine…no problems* but further into the

conversation revealed, *you still hear the monitors and you get that sick feeling - I could hear them in my sleep…. I think that the psychological thing of it just stays with you for a lot longer than the actual physical aspect of what's gone on* [Amanda].

Participant's perception of the physical space indicated they found the SCN a cramped area full of activity. Space limitations, strict routines and an atmosphere of 'busyness', intensified the difficulties for participants during their infant's hospitalisation. Their descriptions of a busy environment referred to other families and visitors as well as nursery activities.

Exposure and 'others'

I just didn't need all those people in there [Susan]

Participants' accounts reflected different perceptions of visiting restrictions with one participant describing a *free range* approach to visitors. Management of visitors varied between staff and hospitals with one unit adhering rigidly to *two at a time* [Jane and Susan] yet in the other SCN, *half the time the staff wouldn't notice…you'd have six visitors all in there at once* [Nancy]. Nancy, aware of the vulnerability of her son to infection, resented the indiscriminate approach to visitors, *they'd just let anyone through the door.*

The perceived voyeurism from visitors was intrusive for some. Susan felt exposed with *all the visitors* [not her own] *that come in and out* and she compared the nursery to a shopping mall with the public *peering at all the babies.* Conversely, Jane found it

difficult to control her own visitors with the nursery regulations of infant privacy and was fearful of reprimands from staff, regarding her visitors looking at other infants. Given the large number of infants in the nursery during her stay and the close proximity, she stated it was difficult to avoid *having a look*; but she would give vigilant instructions to her visitors, *when we go in - don't look - anywhere. Just go to J …don't look at anyone*. Susan *felt a bit uncomfortable with all the visitors* and their inspection and curiosity regarding other infants*…when they're in there for a bit they start to …suss out* [scrutinise and work out] *what's going on around everywhere*. Both participants, with their different perspectives of visitors in SCN, indicated a lack of control [powerlessness].

Some participants described exposure to families outside of their normal social realm. Discriminating language depicted an aversion to some families, but with an apologetic tone; *this might sound, um, a very class based comment but in the public hospital, the majority of people you are exposed to, is different to a private hospital* [Marion]. Marion found choices made by other parents *difficult,* especially related to feeding preferences and referred to the *really young mums who had early babies, and culturally it was different and their expectations…you know, **those*** [Marion's emphasis] *parents.* The comments made related to unsupervised older children, choice of feeding (bottle rather than breast) and families who *smelt;* characteristics which suggested inadequate parenting to participants.

Apart from premature infants, nurseries may also care for sick infants or infants whose mothers are on heroin or Methadone with the infants being admitted for withdrawal and

possible medicating for several weeks. Two participants mentioned drug affected infants in the nursery. Nancy was acutely aware *there were quite a few babies in there detoxing* [drug withdrawal as a result of a woman using drugs of addiction in the pregnancy]. Her disgust was apparent, both in the narrative and her body language, as was her frustration with the inability to control this aspect of the environment. She *barricaded* her son in a corner to minimise exposure to the visitors she considered a risk to him, *the mothers on Methadone and things like that…they'd drag whatever kids in, coughing and spluttering.* The shared social space and lack of personal space was extremely challenging in the context of her own needs, a woman who only weeks before had expected her son to die.

Marion described the nursery as a *shared space*, but space allocated for all became space for only some, due to the reluctance to share social space with others seen as less desirable. Prejudices against lower socio- economic groups manifest themselves in many ways and may have been intensified within the confines of a restricted space, where women such as Nancy with *fragile babies that are so vulnerable* try to safeguard their infants. Nancy was apologetic; *I mean that's a really awful thing to say* [disparaging comments regarding an Aboriginal family's personal hygiene], but candid in her descriptions of other families. She wouldn't use the lounge room because *you didn't want to go in the breastfeeding room, 'cos it smelt*. When her son was well enough to take to the lounge room for breastfeeds, there was a couple *that had a detox baby and they basically took over the feeding room. She was Aboriginal so I don't think she wanted to mix with anyone else. And they certainly were not very hygienic and her partner, he was just revolting, just revolting.* Clearly, Nancy found exposure to these circumstances

disturbing and perceived some visitors as a potential threat to her son. Her negative views and refusal to share a space indicated the lack of control some women felt regarding the social environment. Her narrative suggested staff couldn't or didn't want to dictate or monitor visitors' behaviour.

Marion's reference to the *socio-economic pool* suggested there may have been a number of disadvantaged families within the nursery, parents who were *likely to arrive without a capsule* [to take their infant home in reference to car safety]. The socio-demographic mix seemed particularly complex and intense within a confined space. Some participants, especially those with other children, were also critical of other parents: *I don't know how some of them mums could leave their babies* [Susan] and parents who *just let their kids do anything…laps around the nursery is just not on. I would expect them to be very quiet and that put me in distress because I was fragile* [Marion].

Some participants found the exposure to events confronting within the cramped arena of the nursery. As Marion stated *it's that, that exposure, the public exposure to events like that, that aren't yours* [collapse of an infant and the resuscitation carried out in front of the parents, at the cot next to Marion's daughter] *and from the mother's point of view the public exposure to their distress* [Marion]. Lack of privacy resulted in each participant feeling exposed in various ways. One participant found *hearing* more of an issue than *seeing*, y*eah, there's no privacy. Such a small confined space…You couldn't have a conversation without knowing that everybody in the room was going to hear it and even if I tried not to hear someone else's conversation, you couldn't help but hear it* [Louise].

For most, the feeling of exposure and possible scrutiny by staff was prevailing, although sometimes contradicted in the narrative. There was a definite inhibitive effect of the environment on all participants' behaviour. Karla described it as *really good* when she took her son out of the nursery, *and not feel like everyone, not that everyone watches you but ...* Susan *tried to stay out of there* [nursery] *as much as I could…I just didn't want to be there,* predominantly to maintain some privacy and minimise emotional exposure; *I don't like it that everybody's in there looking at me, and looking at the baby. I didn't like that bit of it…especially days that I just wanted to cry*.

Accounts clearly indicated participants' discomfort with the environment and the difficulty they experienced sharing a confined space with others. Lack of privacy, a feeling of surveillance and a reported broad socioeconomic blend of families resulted in participants feeling the need to take their infants out of the nursery.

Nowhere to go

Several participants described having *nowhere to go* in terms of the restrictions of space and lack of privacy. Their accounts reflected a desire for and a lack of their 'own space' for themselves and their families. There was no dedicated room for parenting, although as described earlier, both hospitals provided small areas for feeding and a lounge room. Nearly all women reiterated the desire to remain with their infants all the time, had it been allowed. *The ultimate would be that you can stay there - you could have your child with you twenty four-seven* [Betty].

The open design of both nurseries, particularly when infants were in open cots which were easily moved, meant most infants and hence their families, had no allocated space. *She* [infant] *was in a parking bay in the middle- it was hard to get a park in there at all sometimes* [Susan]. Louise found it *hard to sit by a cot that's in the middle of the room* and as she explained *it's your baby's home and you need to be able to make it feel like your home, that's really important* [Louise]. Nevertheless, Louise stated it never felt like her infant's home. Creating their own space included dressing the infant in their own clothes and bringing in toys to decorate the cot and *make it more homey* [Louise].

Participants articulated the need to leave the nursery for a number of reasons. Privacy was sought by most participants to avoid constant scrutiny and also create their own space. Amanda felt the nursery needed *an area that the mothers could go to, a retreat, just for 10 minutes* [to] *recharge their batteries before they go back to sitting next to the isolette;* comments like this suggested the strain of continually being in the public gaze of the nursery with her infant. An area like the lounge was seen as being *more homely…you could be a bit more normal around there* [Amanda]. A different environment, particularly one which was perceived to be more *homely* [Betty] and less institutionalised such as the lounge, represented normality in the context of parenting. However, the lounge was a space available to anyone and sometimes women felt less comfortable there than the nursery. *…it's not having anywhere to go…like the TV room - sometimes there were people in there, dads that were visiting, and we'd be trying to breastfeed in there* [Betty] or Nancy deliberately avoiding the lounge with its undesirable visitors.

The creation of their own personal space away from the nursery seemed to give some participants more freedom, *you can just go and do what you want with them* [Karla]. Susan preferred the lounge area with her other children, finding it more comfortable, *I could shut the door, keep the noise in and she* [three year old] *had toys and videos,* although she found the whole hospital environment difficult, *when you're up there with other kids, you've got to try and keep them quiet…you seem to be stressed out straight away. You know, shhh…be quiet, be quiet, be quiet.* Some participants reiterated the need to 'get out' beyond the hospital. Betty believed if she were able to take her daughter out *just down the street,* she would gain a deeper sense of her infant *belonging* to her, a view shared by Karla, *I wanted to take him out…but I didn't ask.* Louise had the experience of taking her son for a walk down the street in Melbourne once he was stable and found the regional hospital's restrictions frustrating. *I think if you're encouraged to take baby out, even just half an hour, you're that step closer to the baby becoming yours. It's my baby and I can take it for a walk instead of spending my life in a hospital*. These participants indicated that taking their infant out in a pram was something a normal mother would do. 'Getting out' generally reflected a desire to feeling like a mother and being wholly responsible for their infant. Ultimately, participants wanted their infants well enough to take home and in one case, a participant was prepared to disregard medical advice and take her infant home early.

Creating their 'own' space within the nursery confines was difficult, especially with the mobility of cots, but dressing infants in their own clothes and bringing in toys was significant to participants. For Betty, providing her daughter with clothes helped her feel

that she was ours, she was wearing her own clothes and having her own teddies. That was really important.

Participants indicated their desire to take their infant out of SCN to a lounge room, in part to gain a sense of ownership but also to tend to their infant in a less clinical environment. The mobility of their infants in portable cots facilitated moving them 'out and about' but also resulted in a lack of 'fixed' personal space within the SCNs for some participants. Activities with their infant were reported as being more restricted in one regional hospital compared to the experiences in Melbourne.

Melbourne to Regional

The five participants who had experienced transfer of their infant from a tertiary centre made comparisons between the two settings, both the environment and the staff. Louise was *warned about …the difference in the level of care* before arriving but didn't specify who warned her. Betty preferred the less intensive approach and recognised it as a clear indication of her infant progressing forward, despite her husband worrying *we've stepped back into the dark ages.* Amanda felt the smaller size of the regional nursery contributed to it being *a bit more relaxed…so they didn't have to have that diligence maybe.* Generally, the transfer represented a step closer to home, medically, psychologically and geographically, and an increasing sense of the baby 'belonging' to them. Betty felt *…once we got home* [to regional hospital]*…I enjoyed it because it was a lot more relaxed, and because I felt like she was our child.* She also felt more *assertive* once back in the

regional hospital, being closer to home and family, and started *taking back control…this is our child and I'm telling you this is what she's doing today.*

While the 'relaxed' approach of the regional centres was welcomed by women after the perceived rigidity of tertiary centres in Melbourne, some were critical of the less intensive approach and the lack of restrictions in some aspects of care. Concern for their infant was one of the main reasons for the criticism. Louise was fearful of her twins receiving another women's breast milk so she provided a tray to keep her milk in, only to have it removed by staff. *It was really easy to pick up the wrong milk…it's all just thrown together in the fridge and I didn't like that.* Nancy, disappointed in staff attitudes and the standard of care in SCN was candid, *for a special care nursery, it was disgusting.*

However, although smaller and with less technological equipment than NICU, participants found some practises in one regional hospital restricting and gave examples of a greater sense of freedom in Melbourne regarding their participation in care. *It was encouraged to do everything for the baby* [in Melbourne] but Louise found less encouragement in the regional hospital, despite gaining some autonomy with her twins' care in Melbourne. *With the tube* [gavage] *feeding, we got quite confident doing it in Melbourne…but some of the nurses* [in regional SCN] *made you uncomfortable if you did things.* Karla, who had no experience of another nursery, felt unrestricted and comfortable participating in most of the care.

Participants experiencing transfer from Melbourne reported a diversity of responses but some indicated adapting to regional SCNs was challenging. The less intensive level of care was perceived as inferior to NICU by some which heightened their concern for their infant's well-being. The closer proximity of the regional SCNs to their home encouraged some participants to make the environment as home-like as they could.

'Home' away from home

The environment was very medical [Marion].

The amount of time spent in the nursery assisted participants in gaining familiarity with the environment and routines. Jane described the nursery as starting *to feel a bit like home,* but preferred to go home between feeds, *just get away from the nursery, because it was so busy.* Narratives reflected various restrictions and institutionalised schedules, incompatible with making a hospital nursery feel like home. *It always had that hospital feel* [Betty]. There was a range of restrictions, including limited after-hours entry to the maternity unit, set feeding routines and constraints on access to infants. Night time produced a different set of circumstances. Several participants felt uncomfortable at night, either in the nursery itself or in the hospital. Marion felt distinctly unwelcome in the SCN at night and described the night staff as *not the people persons*. Comments by others indicated the hospital environment in general was perceived as distinctly hostile, even threatening, at night. Access to one nursery at night was difficult with restricted entry through the emergency department. Jane would often drop her breastmilk off late at night, *I'd have to go through emergency and sometimes that can be the worst thing. And you can be waiting there for 20 minutes to half an hour. And sometimes it isn't a nice*

place to be- that was actually a different side to the hospital…all you want to do is get through that door. Similarly, Susan residing in a parents' flat downstairs, *hated the elevator in the night, that was scary… and I' m waiting for someone to jump into the elevator with me…there'd be guys walking around, some of the patients.*

More than half participants alluded to the need to *keep out of the way,* mindful of the fact they were in a busy hospital area, *you know they* [staff] *just like you to keep your space* [Susan]. In addition, the inability to feel 'at home' in SCN was at odds with the perceived necessity to maintain a performance of a parent who was coping; *I didn't want them to see I as falling apart* [Louise]. Participants were reluctant to display their emotions within the nursery and overt displays of grief, anger and frustration were played out in private. Jane, confided that her friends told her, *why don't you just go in and tell them* [nursery staff] *you want to do it this way,* indicating some resentment with her lack of control within the nursery. Karla wanted to phone the nursery from home but refrained for fear of *once I start, I won't stop* [calling].

Participants' stories indicated a tension between a desire and the difficulty to make their infant's temporary home feel like their own home. Visitation at night was problematic and at times confronting for some participants. Negotiating what they were 'allowed' to do was dependent on their relationship with different staff members in the SCNs.

Staff: ‘It depended on who was working’

For mothers, navigation through the nursery culture was largely dependent on their liaison with staff. Most participants described a lack of control over numerous interrelated aspects and narratives described or suggested various levels of tension. Women referred to some staff they felt uncomfortable with and didn’t trust, especially in relation to caring for their infant; contradictory advice regarding care or management of breastfeeding; a perceived lack of empathy by some staff for the *uncontrollable situation* [Betty] these women found themselves in; and the need to adapt to the different personalities and requirements of staff members caring for their infants. Some participants who had transferred from Melbourne centres made comparisons between staff in Melbourne units and regional staff - there appeared to be greater continuity of staff in NICU, *you developed a relationship with them* [Louise]. Most participants felt the need to ‘prove’ their capabilities as a mother, included abiding by the nursery rules and routines, and in some cases almost assimilating a nursing role. The adherence to the routines required enormous effort as women juggled their other roles to concentrate on the maternal role, within the nursery and develop a relationship not only with their infant but with multiple carers with who they were dependent on for their infant’s well-being.

Dependence and independence

Initially, participants were dependent on staff for assistance with most tasks, but became more independent as days passed, their infants grew and their parenting confidence increased. Jane’s son was in the isolette for only the first few days, *I don’t think I ever*

would have taken him out just on my own…the girls [staff] *would come over and get him out*. The dependence on staff caused some participants resentment and frustration, particularly when assistance was delayed or denied. Nancy described waiting for staff to assist with her son's first bath and her angry disappointment at their lack of response was evident: *I had it* [bath, towels] *all prepared and was really excited…they* [nursery staff] *couldn't be bothered so just ignored me.* Nancy, feeling unsupported, postponed the much anticipated bath for two days, *when one of the really nice nurses came back.* Conversely, Louise began taking her daughter out of the isolette independently, when the nursery staff's workload caused her to wait for long periods, although she stated *they* [staff] *didn't like us to do it ourselves.* The perception of the staff's lack of understanding of the significance of some caregiving tasks contributed to some women feeling unimportant and devalued.

Assuming more care and responsibility was strongly associated with a sense of the infant being their own, *it felt good, I could get her out on my own - she's my daughter and* ***I'm*** [mother's emphasis] *going to cuddle her* [Louise]. With time, women became more assertive in their actions to take over the care of their infant, initiating much of it themselves rather than *just wait until the staff said, 'you can do that'…towards the end, I'd just go ahead and do it* [Amanda]. Jane, described the transition to more independence as, *before you'd stand back, it was almost like asking permission…but as you got more familiar and did your own thing, well they* [staff] *were just helping with the feeds.* Karla described feeling *shocked* by the amount of contact and freedom she had with her son, *they let you take him out* [of the isolette] *when you wanted but s*he still felt

compelled to ask permission before any parenting, *I'd always ask but they'd say, he's your baby*. However, some staff were clearly uncomfortable with parents 'taking over' and were reluctant to relinquish control: when Louise asked a nurse why she wouldn't let her feed her daughter via the naso-gastric tube, the retorted response was, '*I like to do it myself that's all!'*

Participants' descriptions of their interactions with staff indicated differing levels of trust regarding care of their infant and communication.

Trust and distrust

Participants' comments about nursery staff ranged from highly complimentary, *they are just fantastic and do a really great job* [Amanda] to angry criticism, *they just didn't care* [Nancy]. Several participants spoke unfavourably of some nursery staff and narratives reflected nursery staff's inconsistent approach to caregiving. *'It depended who was on* [duty]' was a recurrent phrase throughout the interviews in relation to staff and what women were 'allowed' to do in SCN. Inconsistency among staff regarding permission to tend to the infant in certain ways resulted in women needing to re-establish ground rules every day. *Here* [regional hospital], *the staff rotate…there's always somebody new* [Louise]. *Staff that didn't know me, they would do it* [measure her breastmilk out of the fridge for a feed] *but my husband and I did get a bit upset 'cos we knew we could do it* [Betty]. At other times, with staff she knew, it was *no problem* to prepare the milk. Susan, as an inpatient, had been allowed to have her daughter in her room overnight for several nights, but on the fourth night was told [by casual staff], *she's a nursery baby, she has to*

stay here. Louise found some staff encouraged her to take her daughter out of the isolette and others, *weren't too happy about me doing it.* Similarly, Jane received mixed messages about taking her breastmilk in from home, *some of the midwives would say,'don't worry about it, we'll just top him up* [with formula]*…but then some would say, 'bring it up, bring it up'*. Inconsistencies like this left her confused regarding the importance of her provision of milk and the value of breastfeeding.

Sometimes comments were related to personality, *they just wouldn't warm to me no matter what. Some were just cold…mean and bossy.* Susan, who was residing in the hospital parents' flats, felt so strongly about some staff, she avoided leaving her daughter in the nursery when they were on duty, *I'd think N's not staying in there with you.* Betty's poignant comments illustrated similar concern about some staff, as well as a lack of control over her infant's caregivers, *I would think, I would never let you look after my child* [at home], *yet you **are*** [mother's emphasis] *looking after my child…some of them, they just seemed like they didn't care.*

Not trusting some staff was generally related to the care of the infant; comments indicated a caring attitude by staff was valued more than technical nursing practises, and Nancy differentiated between the two, *staff that seemed interested in looking after babies and parents… that actually cared what they did*, rather than merely *doing the job*. Staff who 'cared' for infants as well as parents, were spoken of warmly, and examples given of the special care and dedication those individuals demonstrated, *they just care so much for them* [Karla]. This type of care was seen to be something beyond *just doing what they*

had *to do, you know, obs time, medication time* [Nancy]. Betty referring to a staff member described her as *fantastic at her job but I didn't like the way she spoke about S* [infant]…*some didn't have any empathy for mothers in our situation*. Conversely, participants who felt more a part of their infants' care found the staff *fantastic…encouraging and supportive* [Jane]. Amanda felt the staff *really make you feel a part of your baby's upbringing* and Karla's comments were similar, *they'd treat them* [infants] *like they're their own.*

However, Nancy had many criticisms of regional nursery staff, and compared them unfavourably to NICU staff, both in standards of nursing practice and caring attitudes. One comment related to their apparent disinterest, *they didn't even want to look at it,* of a *wonderful diary* of her son's stay in NICU, written by Melbourne nursery staff. Nancy, with her background in health, was *paranoid* and expressed a deep mistrust of nursery staff, questioning both their competency and their attitudes. She was fearful of leaving her son in the nursery, *you know the monitor would go off, they* [staff] *might half-heartedly get up and have a look, but after a few days they wouldn't even bother. So basically, it was pretty scary now to actually come home and leave him there. I didn't trust them.* Nancy mentioned several incidents regarding her son's care or her relationship with staff, such as an abrupt phone call from staff when she was acutely unwell with mastitis at home, '*where are you? We can't settle him'*. Incidents such as these left her feeling angry and unacknowledged. Her depiction of the nursery culture was unpleasant, *some of the staff were uncomfortable to be with and their own staff didn't even like them.*

Having trust in the staff was strongly associated with familiarity of individuals yet most participants described a lack of continuity of staff in both regional SCNs. This resulted in women less likely to *develop a relationship* with staff with the need to *go over things, over and over* [Louise], in terms of her daughter's feeding ability, or adverse responses to handling such as desaturations [fall in blood oxygen levels].

The adjustments to the SCN environment and adaptation to becoming a mother varied between participants. Influencing factors included the medical condition of their infant, their own medical condition and their personality and background, including whether this infant was their first child. Within this alien environment, participants struggled to balance a number of conflicting roles.

Women's roles: 'Who am I?'

Participants arrived at the regional SCN through a diversity of circumstances. Most had planned pregnancies, some of which were IVF assisted. One pregnancy was unplanned but all births were unexpected in their prematurity. Half the participants gave birth in the regional hospitals and of those; one set of twins was immediately transferred to Melbourne for intensive care. The other four participants gave birth in Melbourne following transfer for obstetric complications and their infants were transferred back once medically stable. Only one participant had given birth to premature infants previously. Women varied in their assertiveness and this influenced their roles within the nursery.

Despite their differing situations, all participants struggled trying to incorporate their roles within the SCNs into their lives. They struggled to accommodate their own needs, infant needs, family needs, and the perceived requirements of regulations within the nursery including staff expectations. Generally, staff were perceived to have little knowledge, insight or understanding of the other aspects to women's lives beyond the nursery. Women's adoption of roles within the SCN was influenced by events and experiences beyond the nursery. Factors influencing the maternal role included the physical state of the woman and the level of support from friends and family members. Women oscillated between patient role, recovering from Caesarean sections (LUSCS) and/or associated obstetric complications; visitor role, abiding by the nursery and hospital regulations and routines; maternal role, which had different implications for each participant but was strongly associated with producing breast milk, and lastly, her personal role. Similar to the four general themes within the findings, the roles closely overlap and intersect each other.

A Patient

More than half the participants experienced complicated births, LUSCS or medical problems, and three developed complications during the time their infants were hospitalised. The shift from being a patient to becoming a mother of a hospitalised infant was abrupt, difficult and painful, both physically and emotionally. Louise had seen her twins *for a fleeting second* due to her general anaesthetic for an emergency LUSCS and the need for the immediate transfer of her twins to Melbourne. She was determined to see them the next day and countered medical advice, *I made M* [husband] *drive down. They*

[medical staff] *tried to talk me out of it but I said no, so they gave me a shot of morphine and I got in the car and we went.* Some participants expressed resentment at the lack of understanding of their physical and emotional state, and the expectations placed on them by both staff and their families. Nancy suffering with mastitis was *furious, absolutely furious* at the lack of understanding by nursery staff and their insistence that she should come in to feed her son when she was unwell.

The needs of participants within the public arena of the nursery were reportedly unrecognised or unacknowledged by staff for the majority of the time. Marion's transition from severely ill patient with pre-eclampsia to mother of a premature infant was rapid and dramatic. She required two days in intensive care following the birth and four days later was discharged home when her daughter was transferred to the regional SCN. *I wasn't a patient any longer. I was the mother of a baby who'd been transferred to Melbourne…nobody thought to give me any painkillers when I left, I could barely stand.* Marion remained in pain from her abdominal LUSCS wound for several weeks after birth, yet was expected to bath her daughter every day.

Despite telling staff she was *very unwell,* Marion believed she had little support or understanding, *I was dropped, all the focus was on the baby. I wasn't a patient any longer.* Susan developed a wound infection one week after birth and when nursery staff asked the doctor to have a look, *he said, 'I know I'm not supposed to see you because you're not a patient anymore', but he had a look.* Amanda also took several weeks to recover from her LUSCS, *it took me so long to get in the shower and get organised because I was in quite a bit of pain after the caesar.*

A Visitor

Women's self-descriptions within the nursery suggested most felt like visitors to their own infants. They were all too aware the space belonged to someone else and there were rules by which they must abide. Some participants felt as though their infants belonged to the nursery. For Louise, who tried to personalise a space for her twins' to make it 'homey', *I felt like I was just visiting, like they weren't really mine,* and for her, the nursery *always felt like a hospital,* consequently she felt like a visitor the entire time. Jane described the strain of trying to meet the needs of her family within the constraints of the nursery rules, *everybody wants to have a nurse of the new baby, but nobody could…and only two at a time, two at a time* [visiting in the nursery]. *And it had to be quick to get through everyone-it was hard*. Susan, needing privacy and her own space, avoided being in the nursery as much as possible, preferring to take her daughter to the lounge. She strived to be independent with her daughter's care, *I like to do it myself, kind of like what you do when you're home…I didn't know where to get bottles, or how to do bottles there,* but nursery restrictions as well as the expectation she *should know* where things were made it difficult. It wasn't until Susan was home, she thought, *thank god, we can relax now*. Initially, Amanda felt *like a bystander,* observing the nursery activities happening around her but she always felt welcome and gradually instigated most of her infant's care herself.

The feeling that they should be asking permission persisted for most participants until they took their infants home, although almost all infant care was assumed by participants prior to discharge. Visits ultimately end, and for all participants but one who remained in

parent flats, the inevitability of leaving their infant every night signified the end of the day's visit.

A Mother

More than half participants stated they didn't *really* feel like a mother until they took their infants home. For most participants, this role was only partly adopted while their infant was in hospital and there was an overwhelming sense of feeling incomplete: y*ou're going in there every day…I guess you're her mum and you want to do what you think is right but you can't take on that solo role* [Amanda].

You're kind of like a part-time parent. You were there to feed her but you're not really wholly responsible for her. Ultimately when you left, the midwives were there to look after her [Betty].

You're a mum but you're not a mum [Louise].

The inability to have full control and responsibility due to the infants' hospitalisation, seemed to delay the transition to becoming a mother. As Jane described, *you'd stand back a bit…it was almost like sharing him* [with nursery staff]. Karla alluded to the subtle tension between the staff caring for her son as though he was *their own,* which she valued, but enjoying the privacy of the lounge, *so you could have him all to yourself.* Tending to the infants' needs themselves and breastfeeding in particular, helped participants *feel like a mum*. All women breastfed and/or expressed milk for their infants and some narratives suggested this was an obligatory expectation of themselves, for

Nancy to breastfeed was *the least I could do* to…to try and compensate, *I didn't give him a terribly good pregnancy*. Breastfeeding was seen as one way of 'compensation' for their inability to nurture their infant to term, the *lost* time together after birth and their abandonment of the infant. For most women, producing enough milk and learning breastfeeding were stressful but were seen as th*e only thing I could do, that nobody else could* [Betty]. For some participants, the provision of breastmilk was intrinsically linked with the role of being a mother and was exclusively their own:

I was doing something for him that no one else could do…that was my time with him [Karla].

I guess breastfeeding was the only thing, was the main connection that felt you'd even had a baby [Nancy].

Although perceived as one of the main links with the infant, for some participants, breastfeeding reduced them to *a bit like a milking machine, you're there to supply milk* [Betty] and Marion showed me a fridge magnet cow during the interview, *that's how I felt when I was expressing*. Jane made similar comparisons, referring to herself as, *not a very good cow,* when her milk supply *failed* to meet the required quota on her son's chart. Breastfeeding and expressing required ongoing commitment with participants devoting vast quantities of time on a daily basis. Marion juggled her other obligations to maintain her milk supply, *my whole life revolved around the pump…I was very obsessed that I needed to express every three hours to keep it going.* Jane also expressed every three hours, taking her milk into the hospital six times a day, including late at night, with a

daily routine of *express, and then hospital for the tube feed and then later the bottle. I'd try and feed him myself as well.*

It was important for participants to incorporate their role of mother into the nursery culture. Amanda stated, *with everything medical going on, you need to feel a part of it…of being a mother to your baby.* Boundaries sometimes blurred with women taking on some of the roles of nursery staff by filling in charts and giving infants their vitamins. For some participants, *doing all the care* [Betty] represented total independence with their infant and brought them a step closer to being a 'full-time' mother. Some resistance to the rules and regulations empowered women and allowed them to start assuming a maternal role on their own terms. For example, some participants began taking their infants out of the isolette for a cuddle even when they were aware nursery staff might not approve. Developing confidence as well as trust in their own abilities, resulted in some participants resisting authority to achieve a sense of being a mother, managing their infant's care and taking back control of the situation:

I rang E [partner] *and said, I'm going home. I'm going today whether he* [doctor] *likes it or not - she'd put on weight, she was doing good* [Susan].

They wanted her to have the immunisation and I refused. They didn't want her to leave without it. And I said, my decision - not happening [Marion].

Familiarity with both the environment and their infant, combined with increasing confidence in their ability to parent, allowed women to become more assertive within the nursery. This was particularly evident where continuity of staff was lacking:

... you tend to know more, her [infant] *quirky little things and I find that hard to have to say to them, 'no, she does this, she does that'. And it's not their fault – it's just they rotate so often, it makes it hard for them to know* [Louise].

The multiple meanings of becoming a mother were reflected in the diversity of responses, and demonstrated by the difference in Jane's reaction. Apart from being grateful for the support from nursery staff, she valued the learning experience there and considered her role as an 'apprentice mother'. She described her son's admission to the nursery as a *luxury* and a *blessing in disguise* which placed her at considerable advantage over other mothers in the ward who had total responsibility for their infants: *everyone else has to take their babies back with them and they had to do everything whereas we – don't. And you take that for granted a bit… it was a bit like learning on the job. You're in the nursery* [watching staff care for other infants] *and you're going, oh is that what you do!* [Jane].

The meaning of motherhood for these participants was shaped by expectations, past experience and current circumstances. For all women, expectations were shattered with the arrival of a premature infant. As mothers, these women oscillated between extremes, being at home without an infant, to adapting to a maternal role within a highly regulated environment. While participants alluded to staff's expectations of mothering, they also had their own expectations of what it meant to be a good mother, and some were critical of other mothers within the nursery. Comments suggested disapproval of mothers who

visited infrequently, had *uncontrollable children* [Marion] or had infants *detoxing* [Betty].

A Woman: 'Finding the balance'

The arrival of a premature infant had catapulted these women into a frightening and unfamiliar situation. The abrupt change from a state of pregnancy to the expectation to assume a maternal role prematurely was further complicated by the ongoing hospitalisation of their infants. Women's dialogues suggested the difficulty locating themselves within the situation they found themselves. *I was here and there and I was all over the place like a dog's dinner* [Marion].

You're neither here nor there [Louise].

My life was here in the hospital and nothing outside [Jane].

Varying support from family and friends during this period, impacted on the interruption and dislocation from participants' normal lives and their interpretation of the nursery experience.

Some participants revealed aspects of their past of which nursery staff had been unaware. Nancy summed up her experience as *fairly negative,* and fears for her son's safety and well-being were paramount. Towards the end of the interview she revealed how ten years ago, in an emergency department, she had seen the birth and subsequent death of a very premature infant in a cubicle. *And it all came back to me …here I am looking at my son who is this size and they just let that baby die in a kidney dish…at the time, it didn't affect me*. The support she had from family and friends was *brilliant…that's what got us*

through and *everyone was so interested in how he was going*. Other friends relieved her of some of the home responsibilities, including collecting her horses and minding them while her son was hospitalised.

Amanda was dependent on her mother or sister to drive her into the hospital as she was unable to drive until six weeks after her LUSCS birth. Pain, immobility and transport issues impacted negatively on her visiting her daughter. Her cousin had lost a very premature baby seven years earlier, and Amanda, clearly distressed, made reference to this several times through the interview. She described the impact of the nursery environment on her cousin and believed she reacted in a similar way, *like sometimes I find it hard to look at the pictures of her in the isolette and all that kind of thing. It just hits you that way*. She was very anxious about taking her daughter home, saying she was *unprepared* and felt the discharge was announced quite suddenly…*it was quite daunting really.*

Karla described the support from her mother, who spent most days with her as *she was my lifeline…I couldn't have done it without her.* Most participants had good practical support from family members who helped with housework, meals and transport as well as providing emotional support; *my family did a backyard blitz* [Louise]. Women found family support invaluable and felt they were better able to divert their time and energy to their infants. As Jane said, *I'd come home and everything would be done. Really, all I had to worry about was expressing* [breast milk] *and getting back there. Everything else around me was functioning and going on as normal.* Nevertheless, Jane indicated she

found balancing her extended family's expectations (of visiting and cuddling her son) with nursery restrictions extremely difficult and exhausting, *I was under a bit of pressure… well the family was there and… I just found it really tiring and wearing*.

Conversely, Susan and Marion, with limited support and other children, struggled and Marion said, *my whole life was consumed taking care of everybody else.* Although grateful for her husband's help and support, Susan worried about him coping at home; *I had E* [partner] *trying to do everything and the poor man was beside himself, you know. I went home for tea to give E a break* [from domestic duties] *for one night*. Her concern for her infant daughter was matched by concern for her absence at home. Susan struggled as she *tried to please everybody.* Marion's experience of trying to spend time at the hospital while caring for her other three children epitomised the 'juggle' of time, energy and emotions. She felt unsupported by friends, family and hospital staff, all of whom had little understanding of her difficulties and stress. *As a premmie parent you don't get anything and you have to pick up the pieces of your life…I was really shitty with the whole system because there is no care for the parents…not having that support is what affected me more than anything* [Marion]. Both Marion and Louise reiterated the need for *a counsellor or someone* to provide support as well as information regarding available services within and outside the hospital. Louise was *in shock* and Marion, due to ongoing hypertension and feeling overwhelmed by family responsibilities felt *unable to function*; both these women found asking for assistance difficult, yet Louise strongly believed, *it* [having a premature infant] *needs support, I don't think it has that at the moment*. Participants with other children described feeling inadequate parenting their children at

home, as well as their hospitalised infant; in part, this was their own expectations and perceived expectations of nursery staff.

Women's roles within the SCN were also influenced by factors outside the nursery. Routines and regimented feeding patterns dictated the daily activities which were compounded with other family responsibilities; five participants were also recovering from LUSCS and the associated post-surgical pain. Varying levels of assistance at home with other children and domestic chores allowed participants to focus on their parental role, or alternatively struggle with multiple roles on their own. Commitment to the nursery was often associated with guilt due to neglect of other areas of their lives: children, partners and extended family, housework and shopping. Marion's outline of a typical day illustrated her feeling of *fragmentation - my entire life was just taking care of other people. I'd be home* [from SCN] *by one o'clock. So I would have a rest, have some lunch, do some housework, express, then the kids would come home. So, I'd start cooking dinner, deal with them* [homework], *and then express again.*

Conclusion

Past events and current circumstances helped to shape participants' responses to the experience of having a hospitalised premature infant. These findings demonstrate the complexity and difficulty for women in this particular situation. Rapid transition through different and conflicting roles was necessary for some participants who had been gravely ill. The need to be cared for themselves was overridden by the need and expectation to

care for their infant. Physical proximity was challenging with issues of distance and other responsibilities, but was paramount to the women feeling the infant was their own. In addition, limitations with space and the need to share social space at a vulnerable time, was seen as especially difficult. Descriptions suggest participants were able to play a relatively active role in their infant's care but had difficulty negotiating their parenting responsibilities with staff and complying with the nursery's rules and regulations. Dependence on staff gradually succumbed to varying levels of independence and confidence prior to their infant's discharge home. The following chapter will discuss how these findings correlate to existing literature and identify implications for further research and clinical practice as a result of increased knowledge.

Chapter 5: Discussion: Roles and rules

Three dominant themes from the findings of this study will be discussed: dislocated lives, space, and the multiple roles women were required to adopt. Dislocated lives refers to the difficulty participants had in locating themselves physically and emotionally, as well as the disruption to their lives during this time; space refers to spatial perspectives of the SCN environment and how they intersect with participants' experiences; and multiple roles explores the complexity of roles with a dominant expectation of mothering. These themes reflect issues that emerged as particularly significant in this study and have been paid less attention in the literature. There continues to be minimal investigation of mothers' experiences specific to SCNs and sparse research on regional Australian nurseries. Women's perceptions of SCN environments and their roles within add valuable knowledge to a limited body of Australian research in this area.

Dislocated lives

> There are few data available on the effects on the family of long distance perinatal referral, and more research in this area would be valuable (NHMRC, 2000, p. 114)

Women in this study described emotional responses to their infant's premature birth and hospitalisation that included shock, grief, anxiety and guilt. These responses are consistent with findings from other studies of neonatal nursery parents (Holditch-Davis & Miles, 2000; Pederson et al., 1987). However, from a rural and regional perspective,

geographical distance and prolonged hospitalisation of their infant intensified participants' feelings of dislocation and increased the sense of having 'two lives', one in SCN and one at home. Participants were away from the familiarity of their home for most of the day, spending their time in an environment which they attempted to make more home-like. Participants *struggled* and *felt lost* using language and descriptions similar to that in published literature (Hurst, 2001a). 'Emotional chaos' (p. 73) was exemplified by most women in this study, as they sought to make sense of the birth and subsequent hospitalisation of their infant, which they experienced as fragmenting and dislocating their lives (Flacking et al., 2006). Inability to fully adopt a maternal role was distressing and frustrating. Participants' accounts matched Gasquoine's (2005) description of mothering in a 'context of crisis' (p. 186) and correlated with other published literature (Flacking et al., 2006; Lupton & Fenwick, 2001).

Women experiencing transfer of their infants from tertiary centres to SCNs described a conflict of emotions. On one hand, they conveyed enormous relief about the recovery of their infant, sufficient to warrant transfer to a less intensive environment as well as the benefits, both psychological and geographical, of being closer to home. On the other hand, some participants also found the initial adjustment to a less technological environment difficult as they had become accustomed to intensive monitoring in NICU. In addition, a lack of staffing continuity in regional SCNs in this study was perceived as challenging by some participants, and impacted negatively on their sense of control and trust. These descriptions concurred with findings by Bialoskurski et al. (2002) and Hurst

(2001b) where variations and contradictions in care by multiple caregivers, as well as inconsistent information were perceived as confusing for participants.

Separation from their infant was exacerbated by some participant's long distances from regional hospitals, and even longer ones from metropolitan NICUs. Situational conditions, such as distance and limited support, as well as family factors have been identified in other studies as impacting on women's perceptions of neonatal nurseries (Perehudoff, 1990), but generally the effect of distance is under reported. In addition, the regional focus of this research highlighted issues of geographical distances, as well as a contrast between NICU and regional level II SCNs, in terms of women's expectations. Women's feeling of abandoning their infants was overlayed with intense guilt as well as fear of impaired attachment. Most participants lived 'out of town' and travelling back and forth from the hospital heightened the sense of abandoning their infants, by both the geographical distance and the time spent in travelling, which resulted in less time in the nursery. In addition, their lifestyle was an intrinsic part of their identity and the contrast of environments - the quiet rural home setting compared to a densely populated nursery was an added stress for these women. Women described the surreal experience of being in the 'real world' without their infant, for example shopping for baby clothes or going home to an empty nursery to express breast milk. Undertaking activities such as these intensified their perception of being a mother without an infant, aptly described by Louise, *you're a mum, but you're not a mum.* In some ways, their geographical dislocation was a direct reflection of the fragmentation of emotions. It was evident, similar to Boyd's (2004) descriptions that the experience of travelling between the 'alien

nature of the NICU and the apparent normality of the outside world' (p. 81) was stressful for women.

Feelings of dislocation from previous and familiar aspects of their lives confirmed findings by McKeever, O'Neill, & Miller (2002), in which mothers with hospitalised infants experienced ‘abrupt and profound disconnections’ (p. 1024). Mothers’ responses to prolonged hospitalisation of their infant have been explored to a lesser degree, but published investigations reflected similar problems described by participants in relation to separation from their infant. These included negotiating care with nursery staff, lack of control and inability to feel like a mother (Fenwick et al., 2001b; Nyström & Axelsson, 2002). However, salient findings from the present study suggest more of a direct focus on the effect of the social as well as the physical environment.

Factors inhibiting mothering included geographical distance, separation, nursery regulations and spatial issues. It was evident that a significant component of women’s narratives related to spatial practices and the social environment of the nursery, either directly or indirectly. Participants referred to both subtle and obvious control by staff regarding visitation, infant care and nursery ‘rules’ which they found disempowering as well as their own inability to change a space that ‘belonged’ to someone else and was shared with others. Participants’ descriptions of the regional SCNs depicted a far less technological environment than NICUs reported in other studies; nevertheless, most participants found SCN intimidating in various ways and maintained the sense of visitor status for much of the time.

In conclusion, participants' emotional responses correlated closely to those described in published literature but were interwoven with their interpretation of the nursery environment. The social and physical navigation within the nursery and hospital boundaries, as well as issues associated with juggling a life split between the locations of home and hospital, will be discussed in the following sections. Perception and interaction with space dominated the findings.

Space

> *A restricted area …has a set of rules to determine how its boundary shall be crossed and who shall occupy that space* (Ardener, 1993, p. 1).

Space is 'commonly conceived as an expanse extending in all directions' (Delbridge et al. 2003, p. 1801) but complex definitions vary depending on disciplines with Ardener (1993) stating that 'behaviour and space are mutually dependent' with space 'reflecting social organisation' (p. 2). Furthermore, human activity can only be understood within a time and location (Saunders, 1985), as all social life intersects with space; from a spatial perspective the nursery environment was not merely a setting or background. Interestingly, very few previous investigations referred to space, despite discussion of the impact of the nursery environment. In the nursery context, space in this study was identified in terms of physical space - the environmental constraints and power struggles, personal space - the participants' own space, and social space - space shared with others.

Physical space

Figure 3. Hospital nursery 1969. Source: State library of Victoria

The portrayal by popular media of an infant nursery, reminiscent of maternity wards from the 1960s, is symbolic of images with infants in cots lined up in neat rows tended by caring staff and doting parents, all in a safe and nurturing environment. Findings from this present study suggest a different space, one that is opposite to the above description, with participants' accounts of the two SCNs demonstrating a breach of these common beliefs. Conflict between traditional views and the realities of neonatal nurseries in 2005 were evident in some participants' accounts. Boyd (2004) described the NICU environment as 'densely populated with intense people being very efficient' (p.83) and

narratives by participants in my study suggest their interpretations of SCNs were similar. As outlined earlier, NICUs share some similarities but are quite different to SCNs which have less technical equipment and lower staffing ratios due to more physiologically stable infants. However, distress over separation, concern for infant well-being and power struggles between staff and mothers as depicted in NICU research were evident in this study.

Neonatal nurseries are enclosed within the controlled boundaries of hospitals, with coded doors and signs indicating restricted entry. Descriptions of the nurseries in this study specified these characteristics of a clearly marked territory which was the domain of others. Territorial behaviour involves personalisation of a place, in part to express some degree of ownership, and is also associated with the attempt to control space (Altman, 1975). In this research, both women and staff demonstrated territorial behaviour within the nursery. Meaningful attempts to personalise a space or change an existing one, for example Louise's attempt to provide trays for her breast milk were often devalued, and in some cases personal items on infants' cots were removed by staff. This perception of staff lacking recognition of what was important to women confirms findings in other studies (Gasquoine, 2005). Within a broader context, in hospital settings, Fox (1993) described the 'territorialization' (p.110) of patients by nurses which may result in marginalising family carers.

Nursery space was used to achieve a number of ends: to isolate infants from the rest of the maternity unit, control visitors, designate areas for ill or more stable infants and

constantly observe all individuals. The design of SCNs facilitates visibility of all babies by the staff and they tend to be open-plan with the emphasis on staffing convenience (Bowie et al., 2003). All participants described the feeling of surveillance at various times as a consequence of this level of visibility and audibility. The panoptic design of many nurseries for ease of observation of infants results in a 'watchfulness' (Fox, 1993, p. 28) by parents and staff. The effect of such scrutiny was inhibiting and claustrophobic, and undermined some participants' confidence in their parenting ability. Cots are arranged and rearranged to provide optimal visibility of the infants requiring more intense attention. Bruns et al. (1999) examining the relationship between the physical layout of NICU and dimensions of maternal roles, conceptualised the progress of mothers' caregiving roles with movement of the infant around the unit. Although participants in my study clearly recognised their infant progressing as they were moved from isolettes to open cots, most women continued to experience some restrictions of their caregiving activities. Interactions with staff indicated the dominance of nursery staff over mothers which was intensified in the confined space. Some participants, however, attempted to resist these 'spatial forms of social control' (Low & Lawrence-Zuniga, 2003, p. 31) within the SCN environment, and would access the nursery fridge to take out their breastmilk with the knowledge of possible staff disapproval.

Small portable cots, which are used in SCN were often moved about. This physical movement with resultant shifting boundaries is predominantly relevant to SCNs because infants in NICUs are generally in isolettes and less likely to be moved. Women were never sure of the exact location of their infant's cot when they visited and one participant

believed her daughter had died when she saw the empty cot; an empty cot deeply symbolic in the context of new motherhood and for anxious parents with fragile infants, most likely to invoke panic. Participants were environmentally sensitive regarding the location of their infants. The changing placement of cots was disruptive and unsettling, adding to women's feeling of lack of place and control. In some cases, it created increased anxiety, a finding consistent with Rowe et al. (2005), who found that women had an increased 'sense of stability' (p. 20) when their infants remained in the same place within the nursery. Control over the location of patients in hospitals (Cockerham, 1986) was vividly portrayed by participants' accounts of cot positioning by staff and the inability of mothers to take their infants beyond the hospital boundaries. The physical movement of cots by staff within the nursery ameliorated participants' sense of their own territory; in contrast, participants moving their infants' cots out of the nursery strengthened the feeling of control and their own space. Although Bruns et al. (1999) considered the physical layout of the NICU and movement of cots to different areas played an important influence on maternal roles, the impact of the mobility of open cots to women's sense of place in the nursery has not been explored in published literature.

Participants who had experienced NICU prior to regional SCN compared both environments, and conveyed finding the transition challenging. Comparisons included SCNs providing less continuity of staff and lower levels of expertise. In addition, researchers have argued that parents' anxiety may increase following transfer to environments with less intensive monitoring (Boyd, 2004); several participants in the present study related their concerns when monitors were removed from their infants.

These participants experienced difficulty in adjustment to a less intensive level of nursing care. However, despite most infants being physiologically stable, SCNs in this study placed restrictions on parental participation. For some participants, the regional transfer represented an abrupt and difficult shift from patient role to visiting parent role. Women who were hospitalised in the same tertiary hospitals as their infants found themselves discharged several days after birth with little follow-up care. There is little exploration of issues for mothers associated with infant transfer from NICU to the lower level care environment of SCN and this study demonstrates mothers' expectations were neither identified nor met.

Therefore, it was apparent that participants had to navigate their way through a busy, authoritarian environment to access their infant and gain a sense of identity in this temporary home. At a time of transition of becoming a mother, which required change and growth (Nelson, 2003), participants needed time and space to adjust to the new role. Susan's evident relief at finally being home with her infant, *thank god, we can relax now,* revealed the strain of maintaining the social role within the hospital. Lack of privacy added to women's difficulty of adjusting to a new intimate family role and they unanimously sought a space of their own. However, the establishment and maintenance of personal space was difficult.

Personal space

Families tend to define their existence by certain boundaries, including personal space (Altman, 1975), and difficulties in achieving this were evident in women's narratives.

Boundaries between staff and other families were constantly shifting, physically and psychosocially, making it extremely difficult for women to develop personal space. Women in this study used a variety of ways to achieve a degree of privacy and personal space, including physical barricades around one infant's cot or more commonly, physical withdrawal such as moving to a different area, outside the nursery, usually the lounge which was perceived as more home-like. Conflict between the privacy women sought and the sense of crowding they experienced was partially relieved when they were able to take their infant out of the nursery during visits. Similar to findings from Flacking et al. (2006), participants believed having their own space, preferably a room, would have helped the development of a maternal identity and affirm the sense their infant belonged to them.

All but one participant resided in quiet rural areas, some on acres with horses and dogs. They valued space and privacy, characteristics not found in a SCN. The inhibitive effect of the environment on these women's interaction with their infants and their families was conveyed as just as significant, if not more so, as inhibitive nursing actions (Fenwick et al., 2001b). Public exposure inhibited emotions and parenting responses, closely correlating with the 'inhibition of interaction' described by Flacking (2006, p. 75). Negotiating care and responsibility for the infant resulted in power struggles between staff and some participants. Women's attempts to personalise areas such as their infant's cot or create their own territory beyond the nursery, occasionally caused conflict. Accounts of staff's behaviour, both verbal and nonverbal, suggested some defensive responses when women 'overstepped' the boundaries by adding personal items or not

asking permission prior to performing certain tasks. In the context of personal space, environmentally orientated behaviour may be used to achieve privacy (Altman, 1975) and the perceived territorial behaviour of some other families who dominated defined spaces such as the lounge suggested a means of ensuring privacy and regulating social interaction. Participants sought privacy from other families as well as from staff.

The difficulty of 'parenting in public' was evident and has been described by others, (Boyd, 2004; Flacking et al., 2006), but in this study a broader meaning of public was revealed which incorporated visitors, other families and nursery staff. This contributed to women experiencing difficulties in finding personal space. In addition to developing a parental role in an unfamiliar place, women needed to negotiate sharing space with others. According to Altman (1975), physical and emotional energy is expended when trying to maintain a level of privacy within a crowded situation and this may have contributed to the exhaustion described by participants such as Jane who found the experience *tiring and wearing.* Self-evaluation has been described as one of the functions of privacy (Altman, 1975), but in the public arena of the nursery, there was little opportunity for assessment and reflection.

Space and others

Findings from this study indicated power struggles between staff and mothers and factors of space restriction and crowding as causes of tension for women. Nearly all participants made some reference to the difficulties of sharing a space with other families or visitors, their own or others. Many studies described the difficulty of parenting in the public arena

but this was often related to issues of parental role or conflict with nursery staff (Fenwick et al., 2002; Flacking, 2006; Scharer & Brooks, 1994; Wereszczak et al., 1997). The impact of crowding in my study correlated with a definition by Altman (1975), where there was a discrepancy between 'desired and achieved levels of privacy' (p. 105). Participants' accounts indicated a socially diverse group of staff and other parents within a relatively small space. Narratives revealed psychological stress as a result of crowding as described by Altman (1975), with combining factors of noise, light, interpersonal events, inadequate space and past experiences. All participants reiterated the need to get out of the nursery and away from others. The need of women in this study to 'escape' this particular environment warrants further investigation.

The dominance of an authoritarian hospital system, both subtle and overt, and its influence on the behaviour of individuals within, was apparent in some participants' comments. Interactions with staff and staff reactions to women trying to create their own space within the nursery were affected by the influence of the institution: medical dominance, rules, regulations and restricted access, as well as the actual physical space. Although some investigations have alluded to this power (Fenwick et al., 2001b; Hurst, 2001; Lupton & Fenwick, 2001), there is a paucity of literature relating to the intersection of space and power in relation to SCNs. Findings from this study supported literature which indicated women often occupy roles which allow them to exercise power and authority (Ardener, 1993; Wilson et al., 2005), although they may occupy a subordinate role, such as nursing, within the institution. Participants' accounts of some nursery staff described in Chapter 4 suggested characteristics of 'domineering control freaks' as

described by (Wilson et al., 2005, p. 32), and some staff in this study were portrayed as exerting much authority in the regional nurseries. The perceived manner of some staff by participants matched descriptions of authoritarian interactions by staff in Fenwick et al.'s (2001b) study. Boyd's (2004) argument that parents should view staff as 'visitors' in their infant's home [nursery], was naïve and simplistic as an attempt to transform a powerful institution into a home. One regional nursery claimed to promote FCC practise, however, this was not reflected in participants' accounts. In the present study, staff were depicted as directly controlling physical and social space by restricting visitors, directing activities and adjusting cot positions. Nevertheless, changes to nursery environments and culture are likely to improve women's experiences.

Participants' sharing of space with others not of their choosing was often confronting and at times alarming. An increasing body of evidence refers to the physical environment of neonatal nurseries and possible negative impact on parents, in terms of the confined space, noise and high-tech equipment (Bialoskurski et al., 2002; Boyd, 2004). However, few describe the cultural or psychosocial nuances contained within, best described as the 'little tactics of the habitat' (Foucault, 1980, p. 149). Premature birth affects a wide demographic group (Peacock et al., 1995), with the result that older mothers with a long history of infertility and IVF as well as disadvantaged younger mothers may be 'spatially challenged' sharing a small, crowded area for some weeks. Privacy, particularly in a regional context becomes paramount with smaller populations and an increased chance of contact outside the hospital environment. The social proximity lends itself to possible future encounters with families from the nursery where confidential information may

have been informally gathered. Privacy and confidentiality issues in rural and regional areas have been discussed by others (Green & Mason, 2002) but usually from a health providers' perspective rather than health consumers. Further insights into family views related to privacy would be valuable in terms of providing care which meets their needs. Families from a wide range of socio-demographic groups are required to share nursery space and spend time together in close proximity while their infants are hospitalised. Widespread prejudices continue to exist across socio-economic groups, and women from disadvantaged groups (for example, Aboriginal mothers, women with drug addictions and victims of domestic violence) often 'bear the brunt' of such negative attitudes and discrimination (Oyserman, 2001). Participants' accounts indicated they were aware of the socio-demographic characteristics of other families in the SCN which they found undesirable and in the nursery context, possibly detrimental to their own or their infant's health. Children, *who should have been at school* [Nancy], were disruptive and at times unrestrained by parents or staff in the nursery area, as well as presenting a possible health risk through infection. In addition, infants, born to drug-addicted mothers, spend a number of weeks withdrawing from the narcotics (Ludlow et al., 2004); participants in my study expressed both revulsion and pity regarding these infants and their families sharing the space. Some participants indicated frustration with their lack of control over such an environment. The juxtaposition of different individuals is challenging for all families and staff.

Clearly, issues of space impacted in many ways on participants' experiences in SCNs. The confined physical space contributed to women feeling scrutinised by staff and

restricted in their activities. Limitations of physical space intensified the psychosocial aspects of the SCNs by the close proximity. In addition, the impact of crowding and loss of personal space enforced a sense of having *nowhere to go*.

Participants felt emotionally exposed in such a public arena yet felt compelled to comply with role expectations in an environment where there was little relaxation from 'social roles' (Altman, 1975, p. 19). Consistent with published literature, participants' ongoing difficulty of having a hospitalised premature infant was associated with difficulty in developing a maternal role (Flacking et al., 2006; Wereszczak et al., 1997). However, as indicated by findings in the present study, perceptions of participants' roles within the nursery were strongly influenced by the physical layout and nursery culture. The combined impact of physical, personal and social space was a major impediment to the transition to a maternal role. In addition, a visitor role was enforced by the location within a hospital and other roles were rendered invisible for most participants. The multiplicity of roles for these women is explored in the following section.

Multiple roles

> *A person…is a shadow which we can never succeed in penetrating… a shadow behind which we can alternately imagine…there burns the flame of hatred and of love* (Proust, 1920, p. 132)

I didn't feel like there was much of me left anymore [Marion]

The preceding quote from a participant poignantly illustrated the difficulty of incorporating several new roles into a sense of self, which threatened to become 'lost' during a difficult time. In some respects, participants in my study were silhouettes shaded in with a 'nursery mother' role. Assumptions about the roles of women within the family structured in the wider context of society (Hugman, 1991), were evident in this confined environment of patriarchal professionalism. Literature reinforced the notion that transition to and adoption of a maternal role was challenging (Mercer, 2004), more so under these circumstances of prematurity. Participants adopted a multiplicity of roles within the nursery but the maternal role manifested by preoccupation with the infant and a desire to participate in care, dominated all others. The difficulty in the abrupt transition to a new role of mother of a premature infant correlated closely with published literature (Meyer et al., 1995; Rowe et al., 2005). Only one participant reported she had a strong sense of a maternal identity and autonomy, experiencing minimal role conflict. Others indicated they needed to juggle the overlapping and sometimes conflicting roles with varying degrees of difficulty. Within the hospital environment, Hart (1985) described the disassociation of patients from their social identity; for participants, the role of nursery mother tended to dominate their identity. Events beyond the nursery, such as distance to home, family support and number of other children also impacted on women's

perceptions, and have received less attention in the literature. In addition, participants who were recovering from acute obstetric complications straddled the roles of parent, patient, visitor and self. The roles of these women and the meaning they ascribed to them will be discussed in the context of neonatal nursery literature.

A part-time mother

Infants within the SCN require less intensive nursing care and reduced nursing requirements compared to those in NICU, thus providing more potential opportunity for parental involvement. Findings from this study regarding maternal identity in neonatal nurseries correlated to others (Hurst, 2001a) which confirmed both active involvement in caregiving as well as the presence of the infant were required for transformation into a maternal role (Mercer, 2004; Nelson, 2003). Comparable to literature pertaining to NICU settings (Holditch-Davis & Miles, 2000; Hurst, 2001a), expectations of participants and some conflict with staff regarding parental role were evident in this study. However, a diversity of responses from participants regarding the maternal role reflected findings in only some studies. An unexpected finding was the ‘luxury’ of the experience by one participant who felt a sense of relief she could share the parental role with perceived experts while she learnt mothering skills. Her perceived role was that of an apprentice learning the skills of parenting, both directly from staff instruction and indirectly from observation of staff and other parents. Although nurses in a study by Lupton & Fenwick (2001) considered women were ‘lucky’ (p. 1017) having access to parenting education within the SCN environment, this view was not shared by mothers in their study. A large body of literature confirms the overwhelming and difficult nature of mothering in a

general sense (Baber & Allen, 1992; Barclay, Everitt, Rogan, Schmied, & Wyllie, 1997; Rogan et al., 1997), but in the nursery context, difficulty was usually described from the inability to adopt the maternal role.

While physical contact with their infant intensified the sense of being a mother for women, social and emotional aspects of motherhood appeared to be associated with taking the infant from the nursery, to a different area, and ultimately home. Participants who wished to affirm their motherhood socially, by taking their infant down the street, for example, were denied their requests and similarly, the incorporation of their infant into the wider family was hindered by visiting restrictions. Reclaiming their infant by increased participation in care and decision-making enhanced their emotional assimilation into their role as mothers. Few studies explain the meaning of the emotions of motherhood, but Flacking et al.'s descriptions of women needing to be 'more than a physical mother' (2006, p. 75) to their infants paralleled participants' perception of themselves as *milking machines.* Although most participants felt *part-time* in their parenting capacity, all supplied breast milk as a matter of course, which helped to establish their uniqueness as the infant's mother but also required ongoing commitment. Lactation intensified the physical attachment to their infant as a form of physical mothering. Physical aspects of parenting have been identified more readily than the emotional role (Walker, 1998); it was clear from findings in this study that physical and emotional sensations overlapped in the first few months after birth. A sense of maternal identity and 'feeling like a mother' was accentuated for participants when they held their infants and milestones such as the first bath or breastfeed were especially important.

These have been alluded to in the literature as ‘meaningful moments’ of motherhood (Gasquoine, 2005; Hurst, 2001a). For participants in this study, these moments were often compromised because of delay or postponement due to hospital routines, poor communication between staff and parents or deterioration in infant condition. This was a further impediment to the development of the maternal role.

Participants viewed motherhood as their main role and parenting as their primary responsibility. What became evident through this study, was their need to construct a ‘public’ maternal role acceptable to staff expectations and nursery regulations. The efforts participants made to adopt an acceptable maternal role to comply with perceived staff requirements, and work out what they *should be doing* [Louise] shared similarities with findings from other studies (Bruns, 1999; Fenwick et al., 2002; Lupton & Fenwick, 2001). This social role of nursery mother was constructed within participants’ general adjustment to a maternal role. Adapting to strict routines and different staff requirements was similar to findings by Fenwick et al. (2002) in which women worked out ways to best access their infant via a staff-mother relationship. In addition, confounding factors such as medical complications, geographical distance and domestic responsibilities affected regional participants’ emotional and physical availability for mothering.

Participants with other children depicted significant family responsibilities which they saw as exclusively their own. Their experiences illustrated conflicting responsibilities which increased feelings of guilt and fatigue, and also the dilemma of women in families with the 'tension created as they attempt to fulfill their own needs while effectively

meeting those for whom they care' (Baber & Allen, 1992, p. 2). Caregiving within a family context is generally considered a major component of mothering (Richards, 1997; Tong, 1998) and participants in this study felt responsible for maintaining household functioning despite an overwhelming commitment to being with their infant in hospital. Inadequate support by other family members came at great emotional cost and was generally unrecognised by hospital staff. This typified the invisibility of 'caregiving labour by women' (Baber & Allen, 1992, p. 234) as well as the 'ideological pressures' of motherhood which are dictated and defined by society (Richards, 1997, p. 180). Participants' descriptions as primary caregiver within the family unit matched feminist perspectives where 'the care of all bodies…and the processing of men's and everyone else's feelings' (p. 47) has been apportioned to women (Harding, 1991). One participant was so concerned for her husband's welfare, she went home one evening to relieve him of domestic duties, and *give him a break* [Susan]. Participants with limited support struggled with the workload, in part resenting the huge consumption of energy and time but also feeling an irrefutable obligation. The invisible workload and women's persistent undertaking of the burden, in part due to self-imposed high standards, continues and needs to be examined from a feminist perspective (Burns, 1994; Summers, 2003; Tong, 1998).

Unlike women with hospitalised children who have established a maternal role and developed a relationship with their child, women with hospitalised premature infants are at the beginning of the parental relationship (Heermann et al., 2005), with restricted opportunity to assimilate the infant into their family. With one exception, all participants

did not sense a complete transition to a maternal role until after they took their infant home. These findings concurred with other research which reflected a delay in achieving a sense of maternal identity as a result of prematurity and separation (Mercer, 2004). For some participants, the need to comply as a visitor competed with the maternal role in this setting. The expectation that participants go home every evening emphasized their difficulty in feeling like a mother and reinforced their status as a visitor.

Visitor or patient

Consistent with recent published research, the nurseries described in this study were directed by rules and routines (Flacking, 2006; Wilson et al., 2005), many of which were adopted by participants. The emphasis and adherence to nursery routines dictated participants' activities while their infants were in hospital. Hence, there was little control over the 'dailiness of their lives' (Harding, 1991, p.129), as participants with other family commitments struggled to match their visiting time with feeding routines. Hugman (1991) claimed hospital rules were the 'basis of hierarchical control' (p. 74) and the procedures and routines reinforced the loss of control women had within the environment. Interestingly, although participants indicated some resentment of the inflexible routines, in another sense the daily rituals and strict feeding schedules provided some with a feeling of stability in a period of intense dislocation, a finding also evident in Flacking et al.'s (2006) study.

The sense of being a visitor remained for some participants until they took their infant home; perceived visitor status rather than parental role has been alluded to in other

studies of women with hospitalised infants (Flacking et al., 2006; McKeever et al., 2002). In fact, mothers in McKeever et al.'s (2002) study described themselves as 'working visitors' (p. 1026) rather than parents. This blurring of roles between mother and visitor was evident for participants in the present study as they assumed many caregiving tasks while trying to abide by the restrictions of nursery routines and expectations of staff. Mothers with premature infants are conscious of 'maintaining the peace' within the nursery environment, predominantly to ensure optimal care for the infants (Fenwick et al., 2002; Hurst, 2001a). However, in this study, all participants chose to resist the regulations in various ways in order to meet both their own needs and those of their infants, such as one participant breastfeeding more often than she was 'meant to' and another requesting parental accommodation following her discharge because she felt unable to leave her infant. The way some participants undertook certain tasks independently, with the knowledge of possible staff disapproval, correlated to literature where mothers judiciously 'challenged institutional authority' (Hurst, 2001b, p. 69). This was a means of asserting themselves as primary caregivers and taking more control to the best of their ability in the nursery.

The invisible identity of the woman behind her maternal role is less obvious in published literature. First-time mothers such as Jane struggled in modified roles within the family - as a daughter and daughter-in-law, Jane tried to meet the needs of her family wanting to visit, as well as her own and her infant's needs all within the constraints of the nursery. Similarly, Marion and Susan repressed their patient roles and medical needs in order to meet maternal role expectations of their families at home as well as the nursery.

Premature birth is often associated with obstetric complications and surgical delivery. Six of the eight participants underwent LUSCS and were discharged from hospital less than a week later. The pain and discomfort of recent abdominal surgery impacted on many activities and exacerbated issues experienced with transport, housework and self-care. Expectations of the patient role have cultural variations but generally include moderation of caregiving and domestic responsibilities (Hugman, 1991). Nevertheless, some participants inferred staff attitudes failed to acknowledge their recent patient status and their compromised physical and emotional state. In many instances, women were unable to, or chose not to, assert their own needs. The inability of nursery staff to recognise participants' needs was unlikely to assist them in requesting or obtaining social support. Adequate emotional and practical support has been shown to increase maternal well-being when the infant is hospitalised (Bialoskurski et al., 2002; Logson & Davis, 1998).

For most participants, the public face and maternal role they presented within the nursery revealed little of the woman herself. Participants suppressed complaints or strong outbursts of emotion such as anger, which was similar to findings from other studies (Fenwick et al., 2002; Lupton & Fenwick, 2001) in which sacrifices were made in order to conform to both the role of good mother as well as the institutional role of compliant visitor within the boundaries of the hospital (Cockerham, 1986). Participants demonstrated cooperation and obedience, as well as being 'good' (p. 93), behaviour which was partly imposed by the embedded authority of medical dominance within the hospital as described by Rothman (1991). This adoption of compliance in hospital was

also described by Kitzinger (1992), who referred to ‘the power and mystique’ (p. 153) of the medical system and its impact on individuals. The sacrifice of personal needs for organizational requirements was evident for participants within these SCNs.

Self

Perceived loss of identity in general adjustment to parenting is especially prevalent in first-time mothers (Rogan et al., 1997) with role strain readily identified in a general context of transition to motherhood (Mercer, 2004; Nelson, 2003). In the nursery settings of this study, the private self was partly concealed with the emphasis on a developing but constrained maternal role. The infants were the patients and the women were ‘nursery mothers’, a dominating but one-dimensional silhouette of their whole self. For most participants, there was little acknowledgement of their ‘life outside the nursery’ (Fenwick et al., 2001a, p. 587) by staff. Participants’ needs were not always met and their voices often not heard which has been described in neonatal research (Bialoskurski et al., 2002) and also more generally in feminist literature (Harding, 1991). Similarly, Meyer et al. (1995) referred to the ‘invisibility’ of women in the nursery who stress levels were often unrecognised by staff. Each woman brought a different set of experiences and expectations to the nursery and women in this study juggled several different roles which competed and overlapped.

Literature related to patients in hospitals describes the disassociation from previous sources of social identification and any attempts to restore personal identity ‘may be shunned’ [by staff] (Hart, 1985, p. 107). Some participants described similar identity loss with their main form of identification as *just the mother of a baby in the nursery*, and they

attempted to make an alien place more home-like as they adjusted to their own and others' expectations. This was particularly pertinent for participants who felt unsupported, practically and emotionally, as they juggled the multiple roles and workload. Multiple caregivers and a lack of staff continuity depicted in this study concurred with findings of others (Holditch-Davis & Miles, 2000) where inconsistencies in nursing practise and instruction made women's assimilation into the maternal role difficult. Furthermore, lack of continuity is less likely to develop relationships between families and staff, making identification of women's needs improbable (Bialoskurski et al., 2002). In both regional nurseries, minimal staff continuity was evident through participants' narratives; further investigation is warranted to discover if this is confined to regional areas or all SCNs, as well as exploring reasons behind staff placement and rotation.

Conclusion

Participants in this study reflected the diverse experiences of women positioned in families and in society, with disempowerment evident in many narratives. Their position and role construction within a SCN epitomised the difficulty of many women trying to manage their lives in 'the context of sciences and technologies designed and directed by powerful institutions' (Harding, 1991, p. 5). In addition, pressure and expectations from staff for women to visit regularly and provide breast milk, and fit into the role of 'good mother' (Lupton & Fenwick, 2001, p. 1018), correlated with broader expectations of mothering, in which women are devoted to the role to the exclusion of all else (Tong, 1998). The last chapter discusses the implications of this research.

Chapter 6: Future directions

The findings of this study strongly emphasise the need for individualised care based on the understanding of women's unique needs. Participants' stories of difficulties of affirming their assorted roles due to unmet emotional requirements, inadequate practical and emotional support and sensitivity with the environmental space, indicates an obligation for nursery staff to elucidate these needs in order to improve maternal well-being and therefore enhance mother-infant relationships.

Implications for practice

This research provides insights into women's experiences in a specific setting, thus highlighting areas of nursing practice which can be enhanced to improve care to this population. Regional staffing issues to maintain continuity of care should be addressed as a means of better facilitating partnerships between staff and families and minimising the discrepancy between nursing practise and the principles of family-centred care. These findings of women's interpretations of the nursery environment and their roles within, suggest women should receive individualised and sensitive care, with a particular focus on needs of privacy and space. Nursery staff should be aware of the diverse and individual requirements of women visiting their infants and be sensitive to their needs. Insights into women's experiences will assist in providing better care with more specific guidelines for parents; rather than the provision of care that has been described as 'ad hoc and unpredictable' (Callery, 1997, p. 992). Furthermore, given the unique circumstances

of each woman, emotional availability of nursery staff (Boyd, 2004) is more likely to develop a rapport and identify particular difficulties for each woman.

As evident in this study, specific difficulties for each woman may have been managed by additional support and ongoing follow-up. Women with other children may need extra support with their workload of tending 'two families' and specific strategies may need to be developed (Boyd, 2004). Participants in this study sought more control and involvement in the care of their infant as well as a need to normalise the meaning of a mothering role by being allowed to have less restricted access. The provision of a family-centred approach with collaborative, flexible care which promoted family advocacy (Fenwick et al., 2001b) would arguably benefit mothers. Family-centred care as an extension of woman-centred care in midwifery promotes choice, control and continuity of care. Similarly, a midwifery model of woman:midwife collaboration before and during birth can be transposed to a partnership within the neonatal nursery.

Similar to previous findings (Bialoskurski et al., 2002), women sought continuity with familiar caregivers to minimise staff-mother conflict and reduce contradictions in care. Accounts from participants whose infants experiencing transfer from NICU to regional SCNs, demonstrated specific difficulties which are under reported in published research. Tensions existed between relief at being closer to home and the need to adapt to a different, less intensive environment with a different set of rules. Regional centres have an obligation to keep abreast with current trends (SCARCS, 2002), to facilitate the transfer back to SCN for regional women and prepare them for their discharge home.

This would involve ongoing specialised education of regional nursery staff with a focus on family-centred care. In addition, regional units should aim to restore a sense of location as women prepare for their transition home with their infant.

There was a clear discrepancy between the space desired in SCN and the space available. Both findings from this study, and others, suggest a need for changes to the nursery environment, both physical and cultural, to ameliorate some of the social-spatial issues identified. Most participants wanted increased contact and facilities to remain with their infants overnight which reinforced other research (Bowie et al., 2003). Positive comments by one participant about the *setup* of a new tertiary hospital in Melbourne, with larger areas for each infant, in conjunction with other participants' accounts of space limitations suggest this is an important aspect of the nursery to women. Although cost and space constraints may prevent major redevelopments in the short-term, steps should be taken to provide adequate and comfortable facilities with a focus on the maintenance of privacy of all individuals. Suggestions to restore some identity to both infant and parents would include personalising an area which can be defined as the family's own. Bowie et al. (2003) argued that the provision of single rooms encourages parental participation in care by allowing them personal space and access to their infant at all times. Rooming-in, where mothers and babies remain together in a room, provides mothers with the opportunity to become familiar with infant cues and consequently increases their confidence with infant care. In this situation, staff would act as consultants rather than primary caregivers (Klaus et al., 1995). The benefits have been demonstrated in some studies and include empowerment of mothers as well as encouraging them to provide

total care whilst having ready access to staff (Costello & Chapman, 1998). Nursery design can incorporate family-centred care as well as a user-friendly workspace (Bowie et al., 2003) therefore meeting needs of both staff and parents. However, both organisational changes and a review of the nursery culture would be necessary to implement changes to care (Evans, 2000; Heermann et al., 2005). Nursery staff would need to demonstrate a commitment to change for a successful transition. Findings from studies such as this one need to be disseminated to nursery staff working in regional units to encourage discussion about how staff can improve care to these vulnerable families and to increase awareness of the impact and meaning of a confined space.

Recommendations for further research

These findings provide direction for further research. Additional exploration of space and spatial practices in neonatal nurseries should include the social and symbolic meanings attributed by staff, health consumers and visitors to help clarify differences in spatial interpretations. The meaning of personal space for women in SCN environments and a lack of fixed location for cots were examples of spatial aspects which have received minimal attention in literature. Despite frequent reference to the environmental impact of neonatal nurseries, few investigators have adopted a spatial perspective. Furthermore, Andrews (2003) argued for additional consideration to be given to interdisciplinary research between geographical approaches and nursing, which until recently has been limited.

This research also highlights the need to elicit parents' perspectives and involve them in future planning for nursery design, utilisation of space and implementation of care. This is particularly needed in relation to the experience and expectations of women with infants transferred to regional nurseries from tertiary NICUs. Health consumers have recently been involved in the development of a NICU family focus team at the Royal Women's Hospital in Melbourne (RWH, 2004); SCN focus groups consisting of health professionals and parents of recently hospitalised infants would be a valuable means of ascertaining the needs of the infant *and* the family. Women recovering from surgical births had transport issues and believed aspects of their care, which extended beyond the nursery, were overlooked. While some research referred to unmet emotional needs of women (Flacking et al., 2006), other literature alluded to 'stressors' (Affonso et al., 1992) but made only brief reference to unmet physical or situational needs. Issues associated with regionality revealed in this study warrant exploration in the context of rural women separated from their premature newborns. Such exploration should include women from more distant locations – outer rural and remote areas where greater distances are a factor in having their care needs met. Additionally, research incorporating a broader range of rural and regional health care institutions and including comparisons with metropolitan SCNs, to compare distance and transport issues as well as spatial and role perspectives is needed. Further research would include sampling of other regional or rural institutions and comparisons to metropolitan SCNs, to compare distance and transport issues as well as spatial and role perspectives. Facilitating regional focus groups would also provide opportunity to increase parents' involvement. Future investigation exploring regional women's experiences following their premature infant's discharge from hospital would

add to limited knowledge and would help identify issues related to the transition of hospital to home.

Specific research within SCN settings, as a place of transition to home, is required to address needs of families. The Internet may be of particular benefit to women in isolated areas with open forums allowing women to share stories. However, families of low socioeconomic status may have limited access to such services (Sword & Watt, 2005); options such as telephone follow-up or support groups targeting specific geographic areas may be more practical. Few studies from either parent or staff's perspective have explored the juxtaposition of a broad socio-demographic mix in a small clinical area, particularly in the context of a regional town. Indirectly, through participants' accounts, the needs of some disadvantaged women became apparent. As a particularly vulnerable group, the responses of these women to a premature birth are under reported. Socio-cultural issues within a confined space, such a neonatal nursery, require sensitive investigation. Women from lower socioeconomic groups have unique circumstances and there has been little published research on their learning needs in the postpartum period (Sword & Watt, 2005), particularly in the context of prematurity. Early identification and intervention with disadvantaged families and facilitating the mother-infant relationship is likely to improve both family and infant outcomes. There is clearly a need to discover ways to reflect the heterogeneity of women with premature infants.

Findings in context

This study examined the experiences of a specific group of regional, middle-class women, with hospitalised premature infants. These findings do not reflect other groups of women in SCNs such as socially disadvantaged groups, drug addicted or non-English speaking women. Differences in perceptions may be identified among more diverse population groups. In addition, interviewing fathers of premature infants as well as nursery staff would greatly expand the findings of this study and provide a different perspective to the parenting experience. However, despite these limitations, this research provides valuable insight into this unique experience and expands the understanding, thereby offering opportunities to further implement family-centred care and improve outcomes for premature infants and their families.

Conclusion

> The complexity of women's roles as wife, mother and employee [and individual] has increased much faster than has the health and social system in providing support (Mercer, 2004, p. 231).

The breadth of the question in determining perception of roles in the nursery setting encompassed how women saw themselves in the environment, how they felt they adapted and their sense of identity. Descriptions of their roles moved beyond a dominant maternal one and also revealed the environmental role as a feature of social behaviour. Participants in this study navigated their way through the cultural and physical 'terrain' of the SCN with varying degrees of difficulty. The transition to motherhood is interrupted with the birth and ensuing hospitalisation of a premature infant. There is little doubt the transition

to a maternal role is difficult generally, more so with a hospitalised premature infant, and participants in this study viewed themselves predominantly within a maternal role. However, spatial and social issues within the environment disempowered women not only as mothers but also individuals.

Dislocation is defined as ‘put out of place’ (Delridge et al., 1997, p. 546) or as two participants ingenuously described, *neither here nor there* and that is where women found themselves in these circumstances. The disruption and sense of dislocation to women’s lives associated with ongoing hospitalisation of their infant is profound and under acknowledged. The setting of this study revealed a segregated yet public space in which infant caregiving was the predominant task undertaken. Conflict regarding transfer of care from staff to mothers was aggravated by spatial issues. The confined environment impacted on women’s responses both by its physical aspects and its effect on social interaction. Social issues, such as gender and class divisions and their relationship to space have received little attention in published literature, despite the socio-spatial barriers that have always existed in hospitals (Andrews, 2003). Participants’ descriptions and sensitivity with the environment clearly supported the description that ‘behaviour and space are mutually dependent’ (Ardener, 1993, p. 2). However, very few studies exploring the nursery environment use ‘space’ as a keyword, suggesting the innovation of such a perspective. The emerging findings on the behavioural impact and organisational dynamics of the environment in this study indicate a further exploration is warranted and demonstrate enormous potential for the convergence of geographical and nursing research.

The postmodern feminist approach to this study allowed a thorough interpretation of the meaning of women's roles and was particularly appropriate in the context of an oppressive setting within a patriarchal institution. The flexibility of this framework allowed for new insights and the 'unexpected' (Rapport, 2004, p.13) which in this research emerged as a dominant spatial theme and the interplay of the maternal identity with women's other roles. The intersection of a biological predisposition, in the context of hormonal influences and attachment, with social/cultural influences on the developing maternal role (Somerville, 2000) was evident in participants' narratives and reflected ongoing feminist debate regarding the construction and meaning of motherhood (Tong, 1998). In-depth interviewing gave participants a voice and the opportunity for reflection and validation of their nursery experience and also allowed me to 'travel' through the nursery with these women. Other methodological approaches have been used to explore parents' perspectives, however, as a generic approach, interpretive description encouraged me to 'take a risk' (p. 12) during interpretation and thematic analysis of data (Thorne et al., 2004), resulting in an unexpected, yet dominant finding relating to space. Finally, within a feminist framework, an aim was to bring about change, however small, to improve women's circumstances. The first change is my understanding of the broader perspective and discussion with colleagues will be the next step towards the implementation of changes in my own workplace. In addition, dissemination of findings to other neonatal nurseries through publications and neonatal nurse groups will encourage further discourse regarding FCC and nursery practices.

In conclusion, increasingly smaller premature infants are surviving, resulting in extended hospital stays. Premature and sick infants continue to be confined to nurseries secluded from the rest of the maternity unit, and their own families. Figuratively, the 'gestating' infants nestle in the 'womb' of the maternity ward, protected by nursery staff. To support the needs of mothers identified in this study, SCNs need to incorporate changes to practice, develop an increased awareness to nursery culture in order to bring about change, and consider utilisation of space which reflects parent requirements rather than staff convenience. With better physical design and concerted attempts to adhere to nursery practises which fully involve parents, SCNs have the potential to provide support and guidance for women in their transition to becoming mothers. However, the philosophy and practice of FCC must be endorsed with a commitment to change, in addition to modifications to the physical environment if nurseries are to fully embrace the concept. Furthermore, nursery staff need to view women beyond their role of a premature infant's mother and take into account their unique needs as individuals in a unfamiliar place.

Postmodern feminism framed this investigation of women's descriptions of their navigation through 'roles and rules' within SCNs. The aim of the study was to discover women's perceptions of their roles within a specific environment at a particularly stressful time in their lives and elucidate their needs. Findings revealed women's difficulty in becoming mothers in addition to under acknowledgement and relative 'invisibility' of their roles as patients, visitors and individuals. The relevance of location, in addition to roles, became apparent through women's narratives. Socio-spatial

perspectives are comparatively new to nursing and midwifery research but are particularly relevant to the setting of a neonatal nursery and an emerging interest in space is contributing to new knowledge. Findings from this study provide an extension of literature pertaining to mothers of hospitalised premature infants and add a specific perspective from western regional Victoria. Ongoing discourse regarding motherhood, maternal roles and maternal feminism needs to continue within and beyond a feminist perspective.

> What she [the woman] is and the way she conceptualizes her own role is the outcome of all these images of the self, which every day and every hour of the day go through kaleidoscope changes, depending on the situation and the actors (Kitzinger, 1992, p. 204).

Figure 4. Kaleidoscope of a rural sunset

Appendix 1

PLAIN LANGUAGE STATEMENT

Thank for your interest in this project. This letter is a formal invitation for you to participate. I am a research student of the University of Ballarat undertaking a study about mothers of premature babies. I shall be working under the close supervision of Professor Sally Wellard and Ms Rosey King from the School of Nursing and I am also an experienced midwife.

The study aims to give mothers the opportunity to describe their experiences of having a hospitalised premature baby and their involvement in care. It is not designed to assess the care provided by the nursery. The study will give you the chance to reflect over the time you spent in the nursery while your baby was there. Currently there is little known about mothers with babies in special care nurseries, especially in regional areas. While there will be no direct benefit to you, your contributions will add to our understanding and help to improve future care for families.

If you decide to participate you will be asked to:

- participate in an interview of no more than one and a half hours in length at a time and place convenient to you.

- be available for a follow-up phone-call to clarify any issues

An example of an interview question is, *How did you find the nursery environment?*

The interviews will be audio-taped but the tape can be turned off at any time. Your privacy and confidentiality will be respected and you may choose a pseudonym if you wish. The tapes will be stored in a locked cabinet at the researcher's home.

It is unlikely the interviews will cause you any distress, however should this occur please discuss your concerns with the researcher or supervisor and appropriate counselling referrals may be made. You are free to withdraw from the study at any time.

The results of the study including possible quotes from your interview may be published in a midwifery or nursing journal or presented at a conference in the future. However, you will not be identified.

Many thanks for considering participation, if you agree to be involved in the study, please sign the attached consent form and return in the stamped, addressed envelope.

Yours Sincerely

Catherine (Kate) Knox, Sally Wellard & Rosey King

Appendix 2

ARE YOU THE MOTHER OF A PREMATURE BABY BORN WITHIN THE LAST TWELVE MONTHS?

WAS YOUR BABY IN A SPECIAL CARE NURSERY FOR AT LEAST TEN DAYS?

Would you like to participate in a research project?

You will be given the opportunity to share your experiences and reflect back on the time your baby was in the special care nursery. During an interview you will be asked questions about your experience as a mother of a premature baby:

Kate Knox is a researcher and midwife who is interested in hearing your story. Strict confidentiality is assured.
Findings from this study will contribute to knowledge about 'premature mothers' and assist in improving care and support for the families of premature babies.
Please contact the University of Ballarat on 53279671
or email Kate: knoxub@yahoo.com.au

Appendix 3

UNIVERSITY OF BALLARAT

INFORMED CONSENT

4. **Code number (if any) allocated to the participant** . . . .

5. **Consent (fill out below)**

I. . . . . of . . . . . .

. . . . . .
hereby consent to participate as a subject in the above research study.

The research program in which I am being asked to participate has been explained fully to me, verbally and in writing, and any matters on which I have sought information have been answered to my satisfaction.

I understand that: all information I provide (including questionnaires) will be treated with the strictest confidence and data will be stored separately from any listing that includes my name and address

- aggregated results will be used for research purposes and may be reported in scientific and academic journals
- I am free to withdraw my consent at any time during the study in which event my participation in the research study will immediately cease and any information obtained from it will not be used.
- once information has been aggregated it is unable to be identified, and from this point it is not possible to withdraw consent to participate

SIGNATURE: . . . . . **DATE**: . . . . . .

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